

Chapter 9

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In this chapter we use the word 'women with disabilities' rather than 'disabled women.' We do this to remind people that although a disability can prevent a woman from doing certain things, in other ways she is just like other women. She is a woman first.

No matter what causes a woman's disability, she can be just as productive as a woman without a disability. She just needs the opportunity to develop her skills to their fullest.

For more complete information on health care for women with disabilities, see Hesperian's *Health Handbook for Women with Disabilities*. For information about ordering, see the last page of this book.

Women with Disabilities



About 1 out of every 10 women has a disability that affects daily living. She may have difficulties with walking, lifting, seeing, hearing or using her mind. Yet many of these women are never seen or heard. They are often hidden away and do not take part in community activities because they are thought of as less useful and of less value than women without disabilities.

WHAT CAUSES DISABILITY?

Local customs and beliefs often give people false ideas about disability. For example, people may think a woman has a disability because she did something bad in a former life and is now being punished. Or they may think her disability is 'catching' (contagious), so they are afraid to be around her.

Disabilities are not caused by anything a person does wrong. In poor countries, many disabilities are caused by poverty, accidents, and by wars. For example:

- If a mother does not get enough to eat when she is pregnant, her child may be born with a disability (*birth defect*).
- If a baby or young child does not get enough good food to eat she or he may become blind or mentally slow.
- Poor *sanitation* and crowded living conditions, together with poor food and a lack of basic health services and *vaccinations*, can lead to many disabilities.
- In today's wars, more women and children are killed or disabled than are soldiers or other men.

But even if these reasons for disability are eliminated, there will always be persons with disabilities—it is a natural part of life.



1 out of every 10 women has a disability that affects daily living.

Self-esteem

The following letter came from a group of women with disabilities in Ghana, West Africa. But it could have come from any community, because all over the world, women—and especially women with disabilities—are taught not to value themselves.

Our Association was formed in 1989 by women with disabilities to help promote the welfare of the woman with a disability. We have 21 members with various disabilities (sight, hearing, speech, and movement). We hold a meeting once a month to talk about our problems and to try to find solutions.

We all agree that women with disabilities are often *discriminated* against because:

- we are women.
- we have disabilities.
- we are mostly poor.



We are rejected as suitable marriage partners or regarded as the 'wrong' image in the work place. Girls and women with disabilities are often not able to get an education, even when education is available. For example, even in special schools for children with disabilities, boys usually receive priority.

We are unlikely to receive training for any kind of work. We experience abuse—physically, emotionally, and sexually. Unlike all men and women without disabilities, we are seldom allowed to make decisions at home or in the community.

But for each of us in the Association, the biggest problem is lack of self-esteem. We are taught by society not to value ourselves. We are generally considered to be incapable of keeping a man and bearing children, and unable to do meaningful work. Therefore we are considered worthless. Even our extended families only want us if we prove valuable to them.

—Dormaa Ahenkro, Ghana



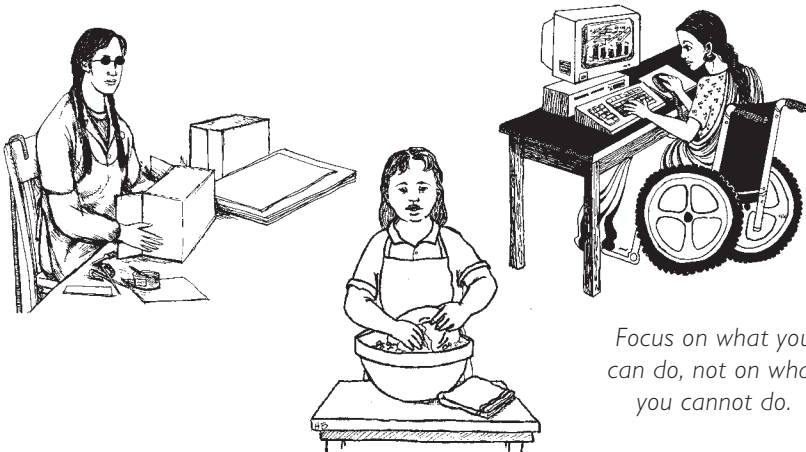
If a woman grows up with the support of her family, school and community to live the best life she can, her feelings of self-worth will be very high, whether or not she has a disability. But if a woman grows up feeling she is worth less than others because she has a disability, she has to work hard to learn to value herself. This process is never easy, but it can be done by taking small steps.

The first step is to meet other people. As other women get to know you, they will find out that women with and without disabilities are not really very different from each other. Each time you go out it will become easier to meet and talk with others.

A second step is to start or join a group for women. Talking with others can help you begin to learn about your strengths and weaknesses. A group can provide a safe place for women to speak freely—if you all agree not to speak outside the group about anything that is said inside the group.

You can also join or start a group for women with disabilities and share your thoughts and experiences about the special challenges that come from having a disability. You can all support each other during both happy and difficult times.

You can support each other in learning how to become independent, too. All over the world women with disabilities are working as doctors, nurses, shop keepers, writers, teachers, farmers, and community organizers. With each other's help, you can begin to prepare for the future, just as any woman would.



Focus on what you can do, not on what you cannot do.

If you have a disability, most of your health problems are probably no different from those of other women, and you can find information about them in other chapters in this book. But the following issues can be of special concern for women with disabilities, especially women with a loss of feeling in the body.

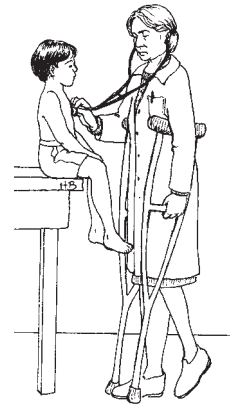
KNOWING WHEN YOU ARE SICK

Some women with disabilities may find it difficult to tell when they have a health problem. For example, a woman who has an *infection* in her *womb* may not be able to feel pain from it. But she may notice an unusual *discharge* or smell from her *vagina* that an infection can cause.

As a woman, you know and understand your body better than anyone else. So if you have an unusual feeling, or body reaction, or a pain somewhere, try to find out as soon as possible what might be causing it. If necessary, ask a family member, friend, or health worker to help.



support groups



Taking Care of Your Health

► *Pressure sores are one of the main causes of death in persons with spinal cord injury.*



SKIN CARE

If you sit or lie down all or most of the time, you can develop pressure sores. These sores start when the skin over the bony parts of the body is pressed against a chair or bed. The blood vessels get squeezed shut, so that not enough blood can get to the skin.

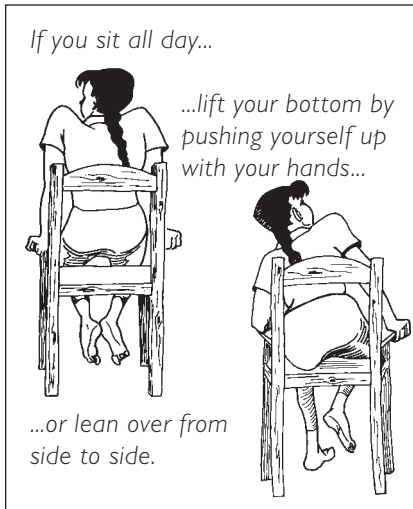
If too much time passes without moving, a dark or red patch appears on the skin. If the pressure continues, an open sore can develop and work its way deeper into the body. Or the sore can start deep inside near the bone and gradually grow out to the surface. Without treatment, the skin can die.

Treatment:

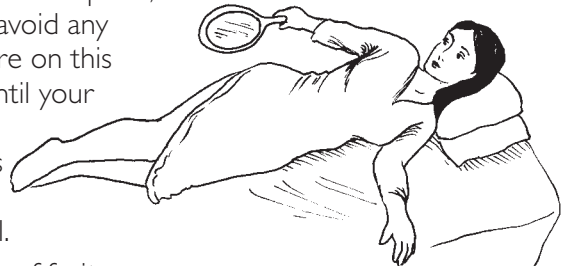
For information on how to treat pressure sores, see page 306.

Prevention:

- Try to move at least every 2 hours. If you lie down all the time, have someone help you change position.



- Lie or sit on a soft surface that reduces pressure on bony areas. A cushion or sleeping pad that has hollowed-out areas around the bony parts will help. Or make a simple cushion or sleeping pad from a plastic bag filled with uncooked beans and rice. It must be refilled with new rice and beans once a month.
- Examine your whole body carefully every day. You can use a mirror to look at your back. If you notice a dark or red place, try to avoid any pressure on this area until your skin returns to normal.



Examine your skin every day.

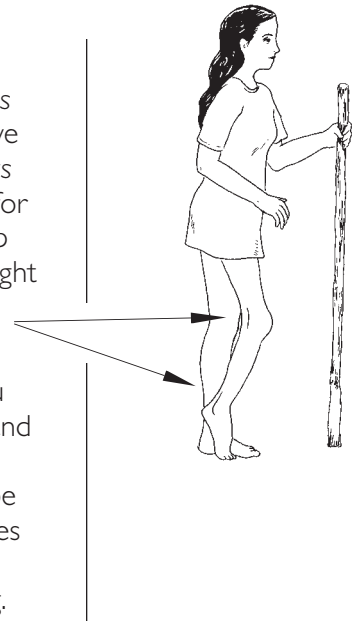


- Try to eat plenty of fruits, vegetables, and foods rich in **protein**.
- During monthly bleeding, do not use cloth or *tampons* inside your vagina to catch the blood. They can press against your bones from inside your body and cause a sore in your vagina.
- Try to bathe every day. Pat your skin dry, but do not rub it. Avoid lotions or oils, because they can make your skin soft and weaker. And **never** use alcohol on your skin.

EXERCISE

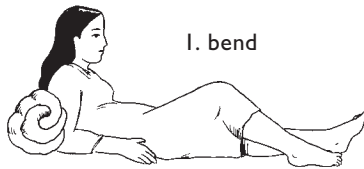
Some women—for example, those who suffer from *arthritis* or *strokes*, or who are in bed because of *AIDS* or old age—have difficulty moving their arms and legs enough to keep their *joints* flexible. When this happens, and an arm or a leg is kept bent for a long time, some of the muscles become shorter and the limb cannot fully straighten. Or short muscles may hold a joint straight so that it cannot bend. This is called a ‘contracture’. Sometimes contractures cause pain.

To prevent contractures and keep your muscles strong, you need to find someone who can help you exercise your arms and legs every day. Try to make sure that every part of your body is moved. If you have had contractures for many years, it will be difficult to completely straighten your joints. But these exercises will prevent the contractures from getting worse and can make your joints a little less stiff and keep your muscles strong.

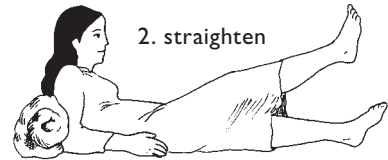


Examples of exercises that prevent some contractures and help keep muscles strong

To exercise the front of the upper leg

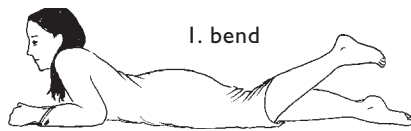


1. bend

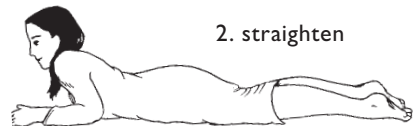


2. straighten

To exercise the back of the upper leg

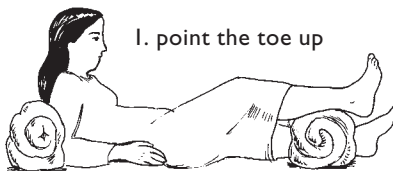


1. bend

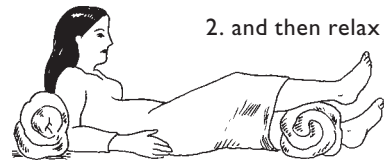


2. straighten

To exercise the lower leg

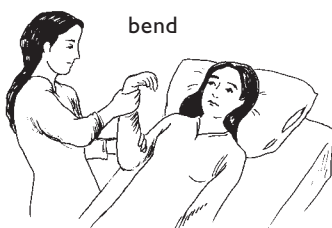


1. point the toe up

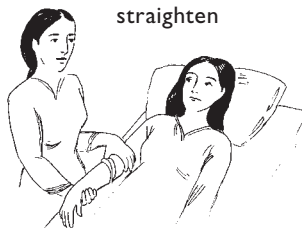


2. and then relax

To exercise the arms



bend



straighten



lift straight up

IMPORTANT If a joint has been bent for a long time, be gentle. Do not try to force it straight.

Sexuality and Sexual Health

► *Be careful not to let other people take advantage of you. It can be difficult to protect yourself against violence and abuse.*



Many people believe that women with disabilities cannot have, or should not have, sexual feelings. They are not expected to want to have close, loving relationships or to become parents. But women with disabilities do have a desire for closeness and sexual relations just like anyone else.

If you were born with a disability, or it happened when you were very young, you may have a hard time believing you are sexually attractive. Talking with other women who have disabilities about their own fears, and how they overcame them, is often the best way to learn to feel differently about yourself. But remember to have patience. It takes time to change beliefs you have held for a long time.

If you are a woman with a new disability, you may already be used to thinking of yourself as a sexual person. But you may not realize that you can continue to enjoy sex. You may think you are not sexually attractive any more and feel sad that sex may be different now.

All women with disabilities can be helped by reading the same information about sexuality that women who are not disabled read. Try to talk about sexuality with them and with trusted teachers, health care workers, and other women with disabilities.

You and your partner will both need to experiment with how to please each other. For example, if you have no feeling in your hands or genitals, during sex you can find other body parts that will create sexual feeling, such as an ear, or breast, or neck. This can also help if a disability has made sex in the vagina uncomfortable. You can also try different positions, like lying on your side, or sitting on the edge of a chair. If you and your partner can talk together honestly, a satisfying sexual relationship can happen. But remember that you do not have to settle for less than you would like. You do not have to have sex with someone who does not care about you.



FAMILY PLANNING

Many girls with disabilities grow up with no information about sex or *family planning*. Yet most women with disabilities can become pregnant—even those with no feeling in the lower body. So if you plan to have sex and do not want to become pregnant, you will need to use a family planning method.

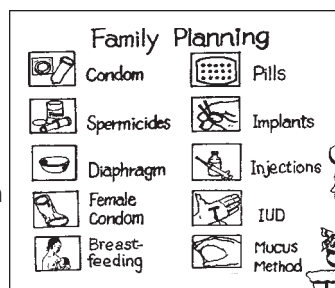
Here are some guidelines for deciding which family planning method might be best for you:

If you have had a stroke, or cannot walk and you must sit or lie down all the time, do not use *hormonal methods*, such as birth control pills, injections, or implants. They can cause problems with blood clots.

If you have no feeling or only a little feeling in your belly, do not use an *intra-uterine device* (IUD). If it is not put in correctly, or if there is a possibility you might get a *sexually transmitted infection*, it can cause an infection. Without feeling you may not be able to tell that you are infected.

If you cannot use your hands well, it may be difficult for you to use *barrier methods*, such as the diaphragm, the female condom, or foam. If you feel comfortable asking your partner, he may be able to put them in for you.

If your disability changes over time, you may need to change your family planning method as your disability progresses.



► Condoms not only prevent pregnancy, they keep you from getting sick with STIs or HIV.



family planning

PREGNANCY AND DISABILITY

A woman with a disability can become pregnant and have a healthy baby. Here are some things to consider, especially if you cannot move your body very much, or if you use a walking aid:

- As your belly gets larger, your balance changes. Some women can use a stick or crutch to prevent falls. Some women may want to use a wheelchair while pregnant.
- Since many pregnant women have trouble with hard stools (constipation), you may need to do your 'bowel program' to remove the stool more often (see page 372).
- During labor, you may not be able to feel the birth pains (*contractions*). Instead, watch for the shape of your belly to change, and use this to count the time between contractions.
- To prevent stiff joints (contractures) and to keep your muscles strong, exercise as much as you can. Try to do the exercises on page 143.
- For more general information on pregnancy and birth, see page 67.



Personal Safety



self defense

Since a woman with a disability may be less able to protect herself, she is more at risk for violent attack and abuse than a woman without a disability. But there are things a woman can do to defend herself. It may help to practice some of these things with a group of women with disabilities:

- If you are in a public place and someone tries to hurt or abuse you, shout as loudly as you can.
- Do something he might find disgusting, such as drooling spit (saliva), or trying to vomit, or acting as though you are 'crazy'.
- Use your stick, crutches or wheelchair to hit or try to hurt the person.
- If the abusive person is someone in your family, try to talk about it with another family member you trust. It may also help to talk about it privately with a group of women with disabilities.



Care for women who have trouble understanding or learning

Women and girls who have problems with understanding or learning may need special care, as it can be even more difficult for them to defend themselves.

If there is a girl or woman in your family with these problems, it is important to talk openly with her about abusive or harmful people. Talk about when it is OK for someone to touch another person in a sexual way and when it is not, and about what is safe and unsafe in public and private situations. Let her know it is OK to tell you if anything she does not like happens to her. Help her learn how to say "No." Teach her how to defend herself.

It is also a good idea to talk with persons with learning disabilities about sexually transmitted infections (STIs) and pregnancy, and to give them what they need to protect themselves (see pages 279 and 224). But be careful not to treat girls and women with learning disabilities like prisoners. When it is safe, let them go outside, or to the market, or to work in the fields.

To build a better life, women with disabilities need health, education, and the ability to move around independently and earn a living. The first step toward achieving these things may be to form a group with other women with disabilities. Together you can decide what things in your community can be changed, in order to make life better for you all.

Here are some suggestions:

- Start a literacy class for the women who cannot read or write.
- Try to get funds—either as a low-interest loan or through a donation—to begin an income-earning project so you can all make your own living.
- As a group, go to the local authorities and ask them to:
 - make the village water supply, schools, and health centers easier to get to, and easier for people who are blind and deaf to use.
 - help you start a library, and to find more information about disabilities.
 - work with you to make disability aids and equipment available.

To give you an idea of what a group working together can do, here is the rest of the letter from the women in Ghana:

Being in this Association gives us a new value, a way to be a part of something which counts, and a chance to organize ourselves for our rights.

Most members have learned skills such as weaving, sewing, candle making, shoe repairs, basket making, and typing. Some of our other activities are:

- Involving women with disabilities in community activities.
- Meeting with teachers and parents to choose materials with positive images of disability.
- Finding ways to support ourselves financially so we can obtain working tools, disability aids, and wheelchairs for our members.

Friendship and trust between women with disabilities gives rise to many new ideas. We run the Association by and for ourselves, and we are encouraged in our efforts. This helps to raise the image of all women with disabilities.



Working for Change

► *The particular tasks your group chooses are not as important as just working together. Start with what you as a group feel is most important, and work from there.*

Just like the women in Ghana, working with others can help you achieve an independent, productive life. You do not have to stay inside your house unless you want to. Go after your dream, whether it is a job, a relationship, or motherhood!