

Chapter 9

In this chapter:

| | |
|-----------------------------------|-----|
| Self-esteem | 140 |
| Taking Care of Your Health | 141 |
| Knowing when you are sick | 141 |
| Skin care..... | 142 |
| Exercise..... | 143 |
| Sexuality and Sexual Health | 144 |
| Family planning | 145 |
| Pregnancy and disability..... | 145 |
| Personal Safety..... | 146 |
| Working for Change | 147 |

This chapter uses the phrase “a person with disabilities” rather than “a disabled person.” A disability may prevent someone from doing specific things, but in most ways, people with disabilities are just like everyone else.

No matter what causes a disability, a person with a disability can be as productive or involved in their community as a person who lacks a disability. Because men may believe that women with disabilities are not able to be “real women,” they are often denied or limited in opportunities. Everyone deserves the opportunity to develop their skills and live their lives to the fullest.

For more complete information on health care and disability, see Hesperian’s *Health Handbook for Women with Disabilities*. For information about ordering, see the last pages of this book.

Living with Disability



About 1 out of every 6 people has a disability that affects daily living, including difficulties with walking, lifting, seeing, hearing, or using the mind. Yet many women with disabilities 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.

Many disabilities are caused by poverty, accidents, and by violence. For example:

- If someone does not get enough to eat during pregnancy, their child may be born with a disability.
- If a baby or young child does not get enough good food to eat, they may develop vision problems or *cognitive delay*.
- Poor *sanitation* and crowded living conditions, together with poor food and a lack of basic health services and *vaccinations*, can lead to many disabilities.
- Wars, police and gang violence, and drug-related conflict lead to disability and death. They also make disability worse by destroying healthcare systems, increasing poverty, and creating refugees.

But even if these reasons for disability are eliminated, there will always be persons with disabilities—disability 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.

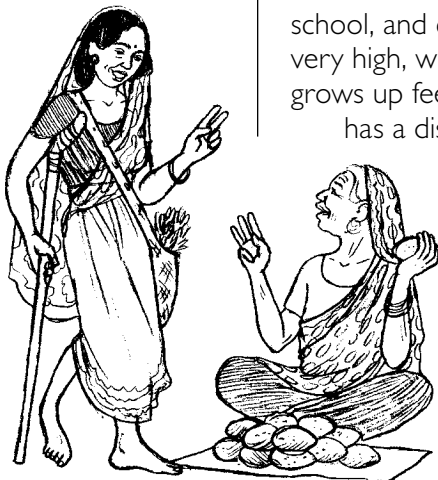


We are rejected as suitable marriage partners or regarded as the “wrong” image in the workplace. Girls and women with disabilities are often not able to get an education, even when education is available. For example, even in special schools for children with disabilities, boys usually receive priority.

We are unlikely to receive training for any kind of work. We experience abuse—physically, emotionally, and sexually. Unlike all people 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



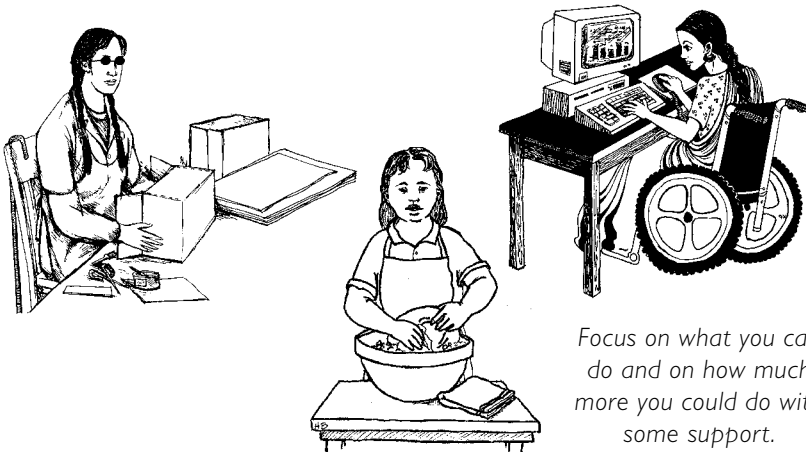
If a woman grows up with the support of her family, school, and community, her feelings of self-worth will be very high, whether or not she has a disability. But if a woman grows up feeling she is worth less than others because she has a disability, she has to work hard to learn to value herself. These personal changes can be helped along by:

Meeting other people. As others 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.

Starting or joining 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 challenges that may arise 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 more independent, too. All over the world, women with disabilities are working as doctors, nurses, shopkeepers, writers, teachers, farmers, and community organizers. With each other's help, you can begin to prepare for the future, just as anyone would.



Focus on what you can do and on how much more you could do with some support.

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

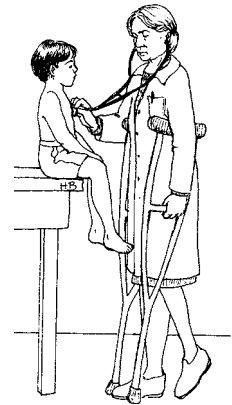
KNOWING WHEN YOU ARE SICK

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

You know and understand your body better than anyone else. So if you have an unusual feeling, body reaction, or pain, 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 much of the time, you can develop pressure sores. These start when skin over bony parts of the body presses for too long against a chair or bed without moving. The blood vessels squeeze shut, so not enough blood gets to the skin, and a dark or red patch appears on the skin. If pressure continues, an open sore can form and grow deeper into the body. Or it may start near the bone and grow to the surface.

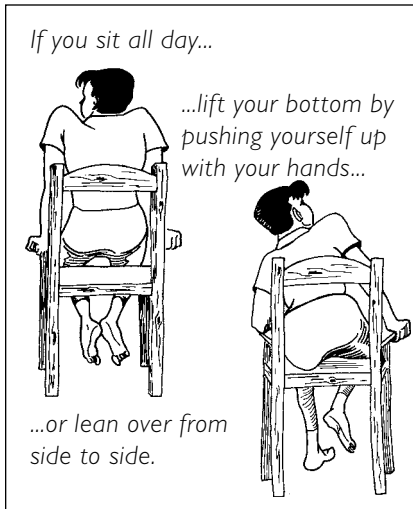
Care for pressure sores so they do not get larger. Because they are dead flesh, they easily become infected. If they get into the blood and affect the whole body, they can cause death.

Treatment:

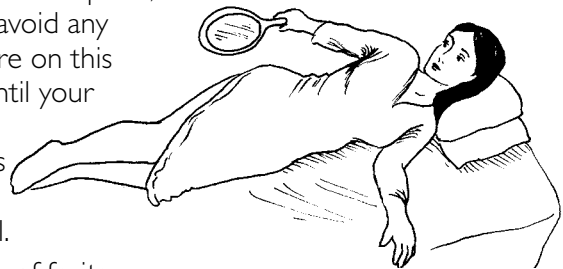
For information on how to treat pressure sores, see page 306.

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 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.

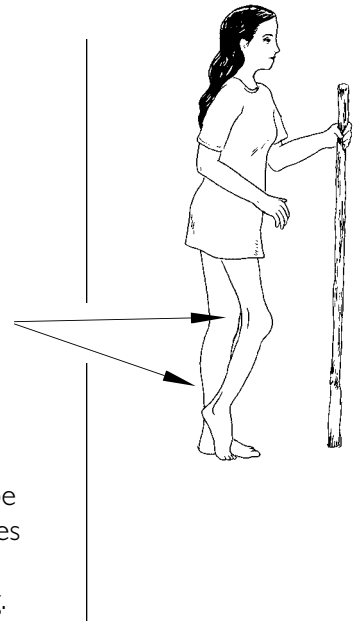


- Try to eat plenty of fruits, vegetables, and foods rich in *protein*.
- During your *menstrual period*, do not use cloth or *tampons* inside your vagina to catch the blood. They can press against your bones from inside your body and cause a sore in your vagina.
- Try to bathe every day. Pat your skin 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

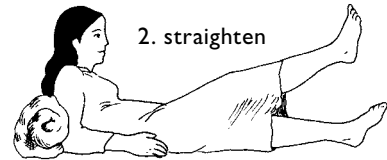
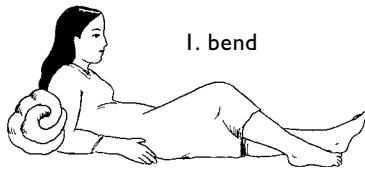
Some people—for example, those with *arthritis*, who have had *strokes*, or who are in bed because of old age—have difficulty moving their arms and legs enough to keep their *joints* flexible. When this happens, and an arm or a leg is kept bent for a long time, some of the muscles become shorter and 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, have someone 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.

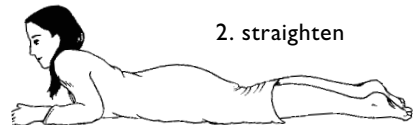
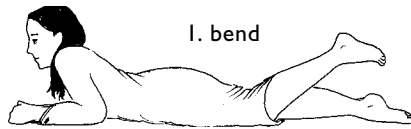


Examples of exercises that prevent some contractures and help keep muscles strong

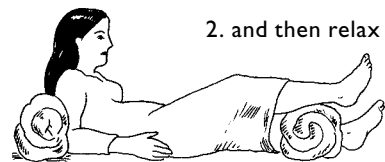
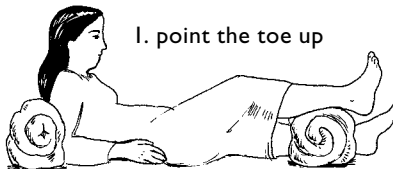
To exercise the front of the upper leg



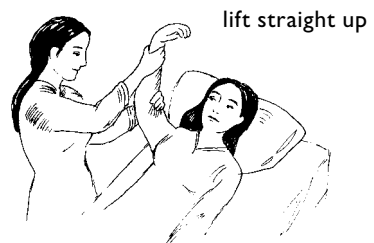
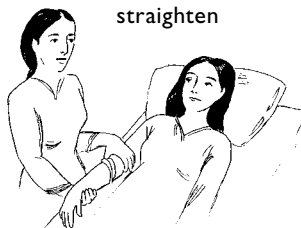
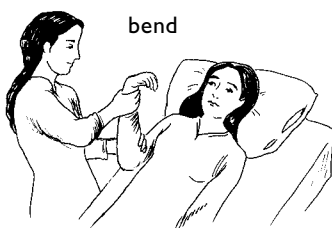
To exercise the back of the upper leg



To exercise the lower leg



To exercise the arms



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

Sexuality and Sexual Health



sexual health

► *You deserve a partner who respects, cares about you and treats you well. For information about protecting yourself against violence and abuse, see Chapter 18, "Violence Against Women."*

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 people with disabilities do have a desire for closeness and sex just like anyone else.

If you were born with a disability, or it happened when you were very young, you may have been taught you were not and could not be sexually attractive. Talking with other women who have disabilities about their own feelings is often the best way to learn to feel differently about yourself. Remember, it can take time to change beliefs that have been held for a long time, even when you are the one holding them.

If you are someone 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 people with disabilities can be helped by reading or discussing the same information about sexuality that those who are not disabled read or discuss. Try to talk about sexuality with trusted teachers, health care workers, and others 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 your ears, breasts, 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. Remember, 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 people with disabilities grow up with no information about sex or *family planning*. Yet if you have a vagina, womb, and ovaries, you can probably become pregnant—even if you have no feeling in your 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.

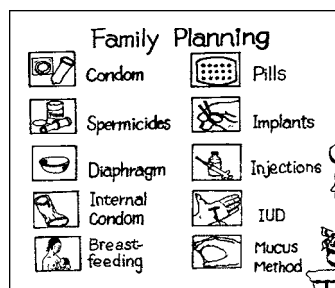
Here are some guidelines for deciding which family planning method might be best for you:

If you have had a stroke, or cannot walk and you must sit or lie down all the time, do not use *hormonal methods* that contain *estrogen*, like combined *birth control pills*, combined injections, the patch, or the vaginal ring. These make *blood clots* more likely.

If you have no feeling or only a little feeling in your belly, it may be harder for you to use an *intrauterine device (IUD)*. You may not be able to feel the signs of complications or check the strings regularly to make sure the IUD is in place. If you feel comfortable, ask your partner to check the strings for you.

If you have difficulty using your hands, it may be hard for you to use *barrier methods*, including the *diaphragm*, the *internal (female) condom*, or *spermicide*. If you feel comfortable, ask your partner to put them in for you.

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



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



family planning

PREGNANCY AND DISABILITY

If you have a disability, you 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 people use a stick or crutch to prevent falls. Others use a wheelchair while pregnant.
- Since many people have trouble with hard stools (constipation) during pregnancy, 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, see Chapter 6, “Pregnancy and Birth.”



Personal Safety



self-defense

Since people with a disability may be less able to protect themselves than people without a disability, they may be more at risk for violent attack and abuse. But there are things you can do to defend yourself. It may help to practice some of these things with other people 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 an attacker might find disgusting, such as drooling, or trying to vomit, or acting like 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 cognitive delay

Women and girls who have cognitive delays that make it difficult for them to learn or understand may need extra attention, as it can be even more difficult for them to defend themselves.

If there is someone 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 she can tell you if anything happens to her that she does not like. Help her learn how to say “no.” Teach her how to defend herself.

It is also a good idea to talk with people with cognitive delays about sexually transmitted infections (STIs) and pregnancy, and to help them access family planning methods (see Chapter 13, “Family Planning” and Chapter 16, “Sexually Transmitted Infections”). But be careful not to overprotect them or treat them like prisoners. Help them move around safely in the community, so they can go to the market, the garden, and other places they want to go.

To build a better life, women with disabilities need access to health care and 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 people 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 those 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, ask the local authorities to:
 - make the village water supply, schools, and health centers easier to get to, and easier for people with different disabilities to use.
 - help you start a library, and to find more information about disabilities.
 - work with you to make disability aids and equipment available for free in the community.

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:

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.*

Being in this Association gives us a new value, a way to be a part of something that 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 among people 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.



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 being a parent!