



CHAPTER 10

Pregnancy

Deciding to have a baby

Getting pregnant is a personal decision, and every woman should have the right to decide for herself if and when she wants to become a mother. But all over the world, women are often pressured by their partners, families and communities to have children, often as many children as possible.

For women with disabilities, however, the opposite is most often true. They are encouraged **not** to get pregnant. Many disabled women are sterilized against their will, so they can never get pregnant. Others who do get pregnant are pressured to have abortions, even where abortions are illegal. This happens because people often believe a woman with a disability cannot be a good mother, or that babies born to her will also be disabled. These ideas are wrong.

There is no reason why most women with disabilities cannot have a safe pregnancy, give birth to a healthy baby, and be a good mother (see Chapter 12). However, there are precautions women with some disabilities must take when they are pregnant, and some women will need more assistance than others.

This chapter has information that will help you understand some of the changes that can happen during pregnancy, how they may affect different disabilities, and how to plan for a safe pregnancy and birth.

Naomy's story: How I became a mother

When I was young and my women friends used to talk about having babies, they all used to tell me that because of my disability, I would not be able to get pregnant. And if by some miracle I did conceive, they said the baby would have to be delivered by caesarian operation and would probably be disabled in one way or another.

I really did not understand what my friends meant, because I knew I was a woman, just like them. But because I walked differently from them, I believed what they said. Also, I had not been examined by any doctors to confirm this. I used to feel very sad, because I loved little children. Every time any of my friends had a baby, I wished it was mine.

In 1987, I started feeling strongly that I needed to try and see if I could have a baby, despite the possible problems. I had a boyfriend and one day I just thought, well, why not? And it happened. On 27 December, 1987, I became pregnant.

When I realized I was pregnant, I was delighted, but at the same time I worried. Because I am a polio survivor, I went to see a doctor, a gynecologist, to prove I was pregnant and to find out if it was true there would be complications during my pregnancy and delivery.

The doctor was shocked to hear I was pregnant. Before he even examined me, he told me that because of the way I walked, I was not going to be able to carry the pregnancy to full term. He said I would lose it within the first 3 months. He advised me not to wait for the 3 months, but to have an abortion right away. I agreed and made an appointment for 27 February, 1988. It was very expensive, but I somehow managed to raise the money.

I had not yet told anyone I was pregnant or about how worried and afraid I was. Abortion is illegal in Kenya, so I did not want anybody to know I was planning to have one. I also did not know how my friends would react. Would they laugh at me or be disappointed with me? I therefore kept the whole thing a secret.



I spent many sleepless nights, and felt sad and afraid all the time. First, I could not stand the idea of not having a child in my life. Second, abortions were dangerous and I had known a number of young women who had lost their lives from having an unsafe abortion. Third, I am a Christian and believe that abortion is a sin. And finally, I was not married and pregnancy outside marriage is not culturally accepted. So you can imagine how troubled I was.

Well, life had to go on. I gathered courage and prepared for the abortion. When the day arrived, I went to the hospital and sat outside the doctor's office waiting to be called in. This was the most trying moment of my life. Courage failed me, and I found myself worrying again about what was going to happen to me. I was sure I was going to die. I started praying for forgiveness and courage.

Suddenly I remembered the doctor saying that I was going to lose the pregnancy anyway at 3 months. This excited me, and I realized there was no need for me to have an abortion. It would be safer, cheaper, and there would be no stigma if I had a miscarriage instead of an abortion. So I went back home to wait for the baby to come out. However, I was not quite sure I had made the right decision.

My first 4 months of pregnancy were horrible. I lost a lot of weight, I had no appetite, and I vomited all the time. Above all, I lived in fear and expected the worst to happen at any time. When I first felt the baby move, I was scared. I thought the time had come for the baby to come out.

For quite some time I was afraid of going for a medical checkup, even though I knew it was necessary. But one day I decided to go to the nearest health center, where I met a doctor who examined me and assured me I was going to carry the pregnancy to full term and that I was going to deliver the baby normally. He did advise me, however, to give birth in hospital.

I felt confident and started going for frequent checkups at the antenatal clinic. The staff told me that all was going well. The nurses also gave me books to read on pregnancy, delivery, and taking care of a newborn baby. These gave me good information and helped give me strength to carry on. All I wanted was to have a baby, see how it would look, see if it was going to be disabled, and above all be called a mother, just like my friends.

To everyone's surprise, I carried the pregnancy to full term—9 months—and delivered normally a healthy, non-disabled beautiful baby girl after 36 hours of labor. My 'baby,' Ann, is now 18 years old, a very healthy girl, and doing well in her studies in form 4 in secondary school.

QUESTIONS TO ASK BEFORE BECOMING PREGNANT

Every woman needs to make plans and decide how many children to have and when to have them. A woman's age, health, and personal living situation can affect her decision to become a mother.

Before getting pregnant, it may help to think about these questions:

- Do you want to have children?
- If you already have children, can you take care of any more?
- Has your body recovered from your last pregnancy?
- Can you care for a child by yourself?
- Do you have a partner or family to help you support and care for the child?
- Is someone forcing you to have a baby?
- Will a pregnancy have any affect on your disability?



WILL MY BABY BE BORN WITH A DISABILITY?

Most disabilities are not passed from mother to child (inherited or familial disability). But there are some that are passed—sometimes by the father, sometimes by the mother, and sometimes by both. See page 14 for more information about some of the disabilities that are passed in families.

If you think your baby might be born with one of these disabilities, it is best for you to arrange to give birth in a hospital in case there are any complications.

WILL THE BABY BE A BOY OR A GIRL?

It is the man's sperm that makes a baby either a boy or a girl. About half of a man's sperm will produce a baby boy and the other half will produce a girl. Only one sperm will join with the woman's egg. If it is a boy sperm, the baby will be a boy. If it is a girl sperm, the baby will be a girl. This is no different for a disabled woman than for a woman without a disability.

In communities where families prefer having boys, women are often blamed if they do not have sons. This is unfair both to girls, who should be valued as much as boys, and to women, because it is the man who determines the baby's sex.

Planning your pregnancy and birth

Around the world, most women give birth at home with the help of a local midwife. These births can be safe and healthy for both the mother and the baby, especially if the midwife is experienced. For women with disabilities, care during pregnancy and birth with a midwife is also usually safe and healthy. But even if the midwife is skilled, there are times when women and babies need hospital care.

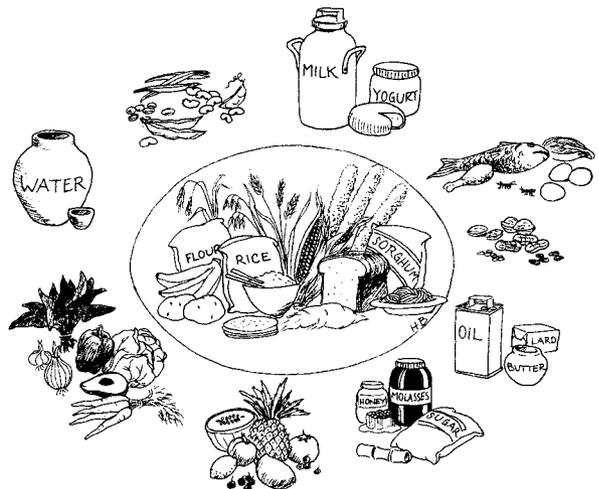


Some women with disabilities who have a greater risk of complications need medical care that is usually only provided in a hospital. For example, if you:

- **have a disability that prevents you from opening your legs wide** such as cerebral palsy, rheumatoid arthritis, or severe muscle spasms. During the birth, you will need to keep your legs open wide for 2 to 3 hours, either by yourself, or with someone's help, or you may need to deliver the baby through an operation.
- **are a woman of short stature (dwarf).** The bones in your pelvis may not be wide enough for the baby to come out safely without an operation. Also, because you have less blood in your body, you may need a blood transfusion, depending on how much you bleed during childbirth.
- **have a high spinal cord injury (T6 and above)** you are at risk for getting dysreflexia, a deadly high blood pressure (see pages 117 to 119).

While you are trying to get pregnant

To make sure you and your baby will be as healthy as possible, eat regularly and try to eat a variety of healthy food, especially the foods that can help prevent birth defects (see pages 86 and 216). Healthy habits like eating good foods, not smoking, and avoiding drugs and alcohol are important because many problems start early in pregnancy—before you even realize you are pregnant.



MAKE A BIRTH PLAN

Even though it can be difficult for women with disabilities to get the medical treatment they need, every pregnant woman should make a birth plan. You should begin having *prenatal* (also called *antenatal*) checkups as soon as you think you are pregnant. If possible, try to find a midwife, doctor, or other health worker you trust, and take a friend or family member with you when you go for your first checkup. Together you can talk about any possible problems that may happen, what can be done about them, and where you can get the best advice. You can use this information to help make your birth plan. For example:

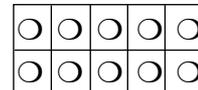
- Which will be the safest place for you to have your baby: at home, a birthing clinic, or a hospital?
- Will you have transport to a hospital or clinic if you need it?
- If you take medicines regularly, will they have any effect on your developing baby? You may need to change some of the medicines you take to others that are safer in pregnancy. This is especially true for anti-seizure medicines (see page 231).
- Will your disability affect your health while you are pregnant, or the health or development of your baby?
- Is your disability likely to cause problems during labor or delivery?
- Can complications be prevented or treated safely?
- Do you know how to stay healthy during your pregnancy (eating well and exercising)?



I will help you while you are pregnant to make sure you get what you need.

How to know when a baby is due

Add 9 months plus 7 days to the date when your last normal monthly bleeding began. Your baby will probably be born any time in the 2 weeks before or after this date.



A woman can know when her baby will be born by counting the passing of 10 moons since her last period.

Staying healthy during pregnancy

If you can take good care of yourself while pregnant, you are more likely to have a safe pregnancy and birth, and a healthy baby. Try to:

- Sleep and rest whenever you can.
- Go for prenatal (before-birth) checkups.
- If you have never had a tetanus immunization, get one as soon as you can. Get at least 2 before the end of your pregnancy.
- Keep clean. Bathe or wash regularly and clean your teeth every day.
- Practice squeezing exercises, if you can, so the muscles in your vagina will be stronger. This will help them recover more quickly after the birth (see page 101).
- Drink at least 8 glasses of water or juice each day and pass urine frequently to prevent bladder and kidney infection.
- Exercise daily.
- Get treatment if you think you have a sexually transmitted infection (STI) or other infection.
- Avoid taking modern or plant medicines, unless a health worker who knows you are pregnant says it is OK.
- Do not drink alcohol, smoke, or chew tobacco. They are bad for you and will harm the baby.
- Avoid pesticides, herbicides, or factory chemicals.
- Stay away from a child with a rash all over its body. The rash may be caused by German measles (rubella), which can harm the baby.
- If you use a bowel program to pass stool, do it regularly (see page 107).

EAT A VARIETY OF FOODS

If you are pregnant or breastfeeding, you need to eat more than usual. The extra food will give you enough energy and strength, and will help your baby grow. As much as possible, try to eat different kinds of food: main foods (carbohydrates), grow foods (proteins), glow foods (vitamins and minerals), and go foods (fats, oils, and sugar), along with plenty of fluids. (For more information about eating well, see page 86.)

Prevent anemia (weak blood)

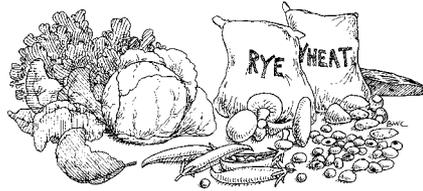
It is especially important for you to get enough food with iron so your blood will be strong. If a pregnant woman has anemia and she bleeds heavily during childbirth (hemorrhage), she is more likely to become seriously ill or even die. For more information about anemia, see pages 87 to 88.

Folic acid (folate)

Not getting enough folic acid can cause anemia and can also cause severe birth defects in the baby, such as growths on the spine or in the brain. To prevent these problems, it is most important for you to **get enough folic acid before you get pregnant and in the first few months of pregnancy.**

These foods contain a lot of folic acid:

- dark green leafy vegetables
- meat (especially liver, kidney, and other organ meats)
- peas and beans
- sunflower, pumpkin, and squash seeds
- whole grains (brown rice, whole wheat)
- fish
- eggs
- mushrooms



Some women also take folic acid pills.

Folic acid pills

Take 0.5 to 0.8 mg (500 to 800 mcg) folic acid by mouth, 1 time each day.

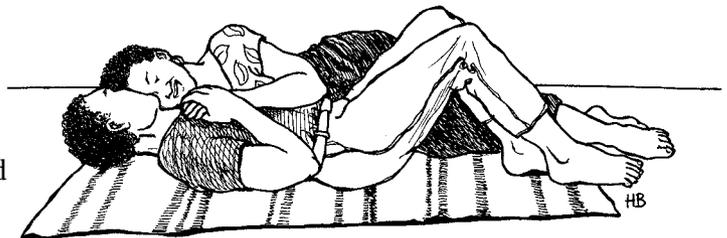
Women who have spina bifida should take 800 mcg folic acid by mouth, 1 time each day.

SEX DURING PREGNANCY

Some women do not want much sex when they are pregnant. Others want sex more than usual. Both feelings are normal. Having sex and not having sex are both OK for the woman and her baby. Sex is not dangerous for the baby.

Sometimes sex is uncomfortable in pregnancy. Depending on your disability, you can try different positions until you find something that is comfortable for you. It may feel better with you on top, or in a sitting or standing position, or if you lie on your side.

Of course, couples can be close and make each other happy in ways other than sex. Some couples touch and massage each other's bodies. Some talk about their hopes and dreams for the future.



Safer sex

If you are pregnant and have sex, it is important to avoid infection by making sure that anything put inside your body is clean. This includes the penis and hands. A man who is having sex with more than one woman must always use condoms—including with his pregnant partner. Condoms are a good way to prevent infections, HIV/AIDS, and other illnesses. See pages 189 to 192 to learn more about condoms.



Condoms are a good way to prevent infection during pregnancy.

Sex and early labor

If you have had a baby before, and you went into early labor, it is probably best for you not to have vaginal sex after the 6th month. This may help prevent you from going into labor too soon.

The 9 months of pregnancy

A pregnancy usually lasts for 9 months and is divided into 3 parts that each last about 3 months. During each of these 3-month parts, a woman's body goes through many changes.

MONTHS 1 TO 3

When you first become pregnant, and the baby starts to grow, your breasts begin to swell and may be tender. You may feel more tired than usual and also have nausea and some vomiting. (In some places, this is called 'morning sickness').

MONTHS 4 TO 6

Many women enjoy the 4th, 5th, and 6th months of a pregnancy. Usually they stop feeling sick in the stomach, stop feeling tired, and have a lot more energy. This is also the time when the belly gets bigger, the baby starts to move, and you can hear the baby's heartbeat.

MONTHS 7 TO 9

This is an exciting time during your pregnancy. You will feel the baby move every day. At the same time, your belly is getting bigger and bigger and, depending on your disability, you may be having more difficulties or problems getting through the day. If you experienced difficulties during the first 6 months, these may continue and may even get worse.

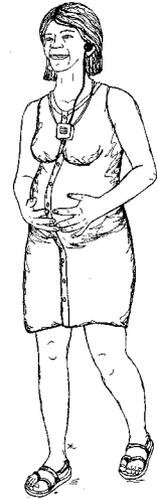
During the last month, about 2 weeks before birth, the baby often drops lower in the belly, especially first babies, and you may find it easier to breathe.

What to expect

Feeling the baby move

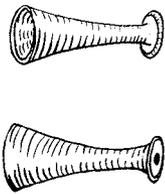
For most women, feeling the baby move inside the belly is the most exciting part of being pregnant. And most women, regardless of their disability, seem to be able to notice the movement, although the sensation can be difficult to recognize at first. Many women describe it as a fluttering movement, and others compare it to gas in the stomach or intestines. Some notice a feeling of pressure inside the belly and then use their hands to feel the movement.

When the baby starts to move in the 4th month, the movements will be very soft and you may not feel them every day. But by the 5th month, you should feel them every day (not all day long—there will be periods of rest in between movements). If you are concerned because you have not felt the baby move for several hours, eat or drink something and then lie on your side in a quiet place for about 30 minutes. During that time you should feel the baby move at least 3 times. If you do not feel or notice any movement, talk with a midwife or health worker.



Hearing the baby's heartbeat

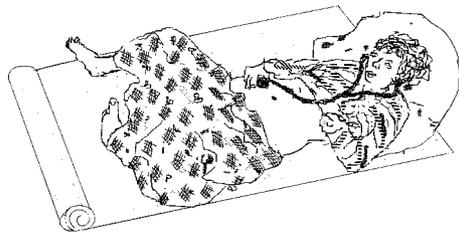
This can be done after about 5 months and gets easier to do as the pregnancy gets more advanced. A baby's heartbeat is very quick and quiet. It is not an easy thing to hear, even for someone with better-than-average hearing, and it is even harder to feel. A birth attendant or health worker can use a fetoscope to listen to the baby's heartbeat. It is difficult for the mother herself to do unless she has a stethoscope (like the one used for taking blood pressure).



Fetoscopes



A one-ear fetoscope can be used to hear the baby's heartbeat.



The baby's heartbeat is quiet and quick. It may sound like a watch ticking under a pillow, only faster. The baby's heartbeat is about twice as fast as a healthy adult heartbeat. You can listen to it yourself with a stethoscope.

Losing a pregnancy (miscarriage)

Women with disabilities are no more likely to have a miscarriage than women who are not disabled. Losing a pregnancy is hard for anyone who wants to have a baby, but it can be especially hard for a woman with a disability. Many people may not think she should get pregnant anyway, and when she does, she will face disapproval in her community. If she has a miscarriage, people assume it is because of her disability. She may think that too.

Miscarriages most often happen during the first 3 months of pregnancy. A miscarriage can happen for many reasons, such as:

- unhealthy eggs or sperm
- a problem with the shape of the womb
- growths (fibroids) in the womb
- infection in the womb or vagina
- an illness, such as malaria
- heavy work or accidents
- poisons
- malnutrition
- emotional stress or trauma



Losing a pregnancy is common. If it happens to you, it does not mean you cannot have a healthy pregnancy the next time.

If you have a miscarriage, take good care of yourself for a few days. This can help prevent you from getting an infection and will help your body heal faster. Try to:

- Drink plenty of fluids and eat nutritious food (see page 86).
- Rest often.
- Avoid heavy work for 7 days.
- Bathe regularly, but do not wash out your vagina (douche), or sit in a tub of water until a few days after your bleeding stops.
- Use clean cloths or pads to catch any blood, and change them often.
- Do not put anything inside your vagina, and do not have sexual intercourse, for at least 2 weeks, and not until a few days after you stop bleeding.
- Wait until you have had your monthly bleeding 3 times before trying to get pregnant again. If you wait, there is less chance of having another miscarriage.

Having a miscarriage, whether early or later in a pregnancy, can cause enormous emotional pain and sadness. It can be worse because the people around you may expect that when the pains in your body have gone, you will be fine again. They may not realize how sad you may feel.

Give yourself time to feel sad and cry. Spend time with friends who understand how you feel and don't force yourself to 'be happy'. Some people may suggest you try to get pregnant again right away. Take time to feel ready for another pregnancy.

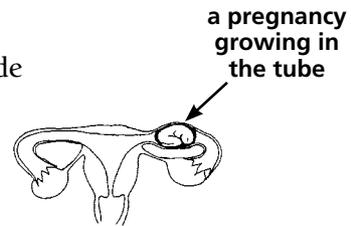
PAIN IN THE LOWER BELLY (ABDOMEN)

Strong, constant pain in the first 3 months may be caused by a pregnancy growing outside the womb in the tube (a tubal, or ectopic, pregnancy). As the tube stretches, it causes pain. If the pregnancy grows large enough, the tube will burst and bleed. This is very dangerous. You will bleed inside your abdomen and may die.

Signs of tubal pregnancy:



- missed monthly bleeding
- pain in the lower abdomen on one side
- slight bleeding from the vagina
- feeling dizzy, weak, or faint



If you have some of these signs, go to the nearest hospital.

BLEEDING DURING PREGNANCY

Do not worry if you spot or bleed a little during the first 3 months. This is not unusual, especially if there is no pain or cramps.

But you must **go to a hospital for medical help right away if you have:**

- bleeding as much as monthly bleeding at any time during your pregnancy.
- bleeding with pain at any time during your pregnancy.
- bleeding with no pain after the first 3 months.

Discomforts during pregnancy

Many women experience discomfort during pregnancy. For some disabled women, the discomforts of their disability get worse, and for some they lessen.

Some discomforts of pregnancy, such as tiredness or back pain, are common to all women, including women with disabilities.

You know your body better than anyone else. So when you are pregnant, pay attention to what is normal for your body and what is not. This way you can tell if something is caused by your disability or by the pregnancy.



What can be different for a disabled woman, though, is knowing if a problem is caused by her pregnancy or her disability. Be aware of what is normal for your body so you can tell the difference. Then you will be better able to get help when you go to see a health worker.

If you tend to get certain problems because of your disability, such as infections of the urine system because you have a spinal cord injury, then you may have these problems more often during pregnancy. Problems may improve or worsen at any time during your pregnancy, depending on your body and the baby's development.

Each and every woman makes adjustments in her life to accommodate her pregnancy.

Here are some changes that women with some disabilities might go through and suggestions for how to deal with them.

FEELING TIRED AND SLEEPY

Most women feel tired and sleepy during the first 3 or 4 months of pregnancy. For more complete information about other possible causes, read about:

- anemia (*Where Women Have No Doctor* page 172).
- not eating enough of the right kinds of food (*malnutrition*), (*Where Women Have No Doctor* page 165).
- emotional problems (*Where Women Have No Doctor* page 416).

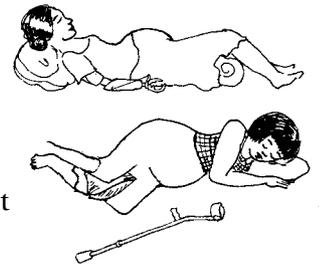
SLEEPING DIFFICULTIES

Many women have trouble sleeping at night during the last few weeks of pregnancy. This can happen because they need to pass urine during the night, or because of leg cramps (see pages 222 and 225), or because the baby starts to move and kick. It can be difficult to find a comfortable sleeping position. If possible, try to rest during the day to make up for the loss of sleep.

It is important to find a comfortable sleeping or resting position, but avoid sleeping flat on your back. This can cause your womb to press on the blood vessels in your belly and cause circulation problems. It can also cause problems with digesting food, with back strain, and with breathing.

What to do:

- Drink a little warm milk or hot soup before trying to sleep.
- Sleep sitting up a little, or with something behind you to support your head and shoulders, and put rolled-up cloth or newspaper under your knees.
- Sleep on your side. If possible, lie on your left side as this is the best position for blood circulation. Place something comfortable like rolled-up cloth or newspapers between your knees and ankles.
- Eat nutritious food, making sure to get enough protein, and use only a little salt in your food (but do use a little).



SWOLLEN FEET AND LEGS

Many women have problems with swollen feet and legs during pregnancy, especially in the afternoon or in hot weather. Swelling of the feet is usually not dangerous, but severe swelling when you wake up in the morning, or swelling of your hands and face anytime, can be signs of pre-eclampsia (toxemia of pregnancy, see page 232).

To help with swollen feet and legs, try to lie down on your side for 30 minutes, 2 or 3 times a day. It does not matter which side you lie on. Just sitting with your feet up is not enough. It is best to lie down on your side.

To help prevent pre-eclampsia, eat nutritious food, make sure to get enough protein, drink plenty of water, and use only a little salt in your food (but do use a little).

MOVEMENT AND BALANCE

During the 9 months of your pregnancy, your body shape will change so much it will probably affect how you move about. This happens to almost all women, whether or not they have a disability. You may find that you start to lose your balance and fall easily. Or that you have problems with bending and picking things up. Because of this, many women with disabilities that affect body movement start to use aids to help with walking and moving about until the baby is born.



AMPUTATED LEG

If your leg or part of your leg is amputated, and you use an artificial leg, you may find that the prosthesis will not fit properly because your body is heavier and the skin above your amputation has become swollen. If possible, talk with the person who made your artificial leg to see if it can be adjusted. If not, you may need to use crutches, a walker or a wheelchair while you are pregnant.

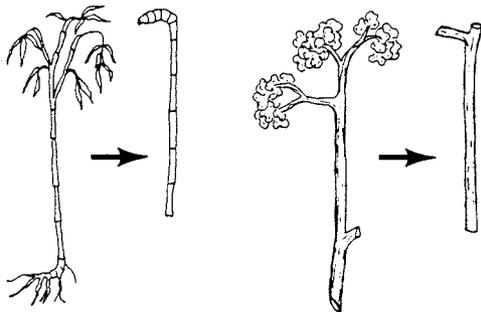


Some women who do not usually use a wheelchair will have to use one while pregnant. You may find it difficult at first to use a wheelchair, but with practice you will find it more comfortable than trying to get around without one.

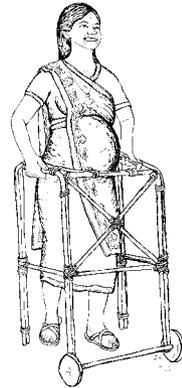
What to do:

A 'walker' can be made from cane, rattan, bamboo or wood. Tie the joints with any strong string, twine or ribbon, or with strips of car tires or bicycle inner tubes.

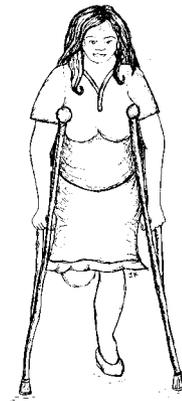
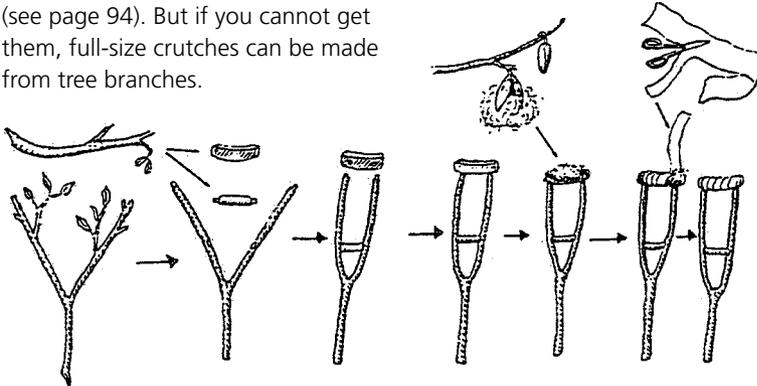
A walker with 2 front wheels is easier to move than a walker with no wheels, and is more stable than a walker with 4 wheels.



A cane or walking stick can be made from forest plants.



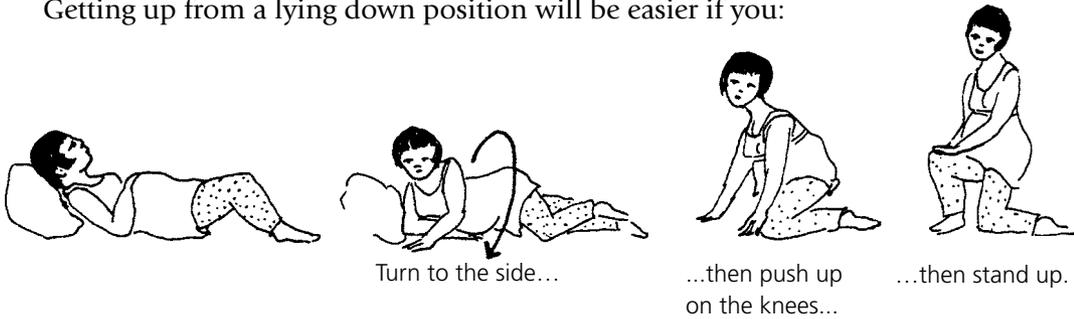
Elbow crutches are the best to use (see page 94). But if you cannot get them, full-size crutches can be made from tree branches.

**Moving during the last weeks of pregnancy**

Even women who are not disabled often have difficulties with balance and with moving about during the last weeks of pregnancy. The difficulties are even worse for women with physical disabilities such as paralysis of the lower body, or limited control of muscles. Your large belly will affect daily activities such as washing yourself, dressing, and moving from place to place.

What to do:

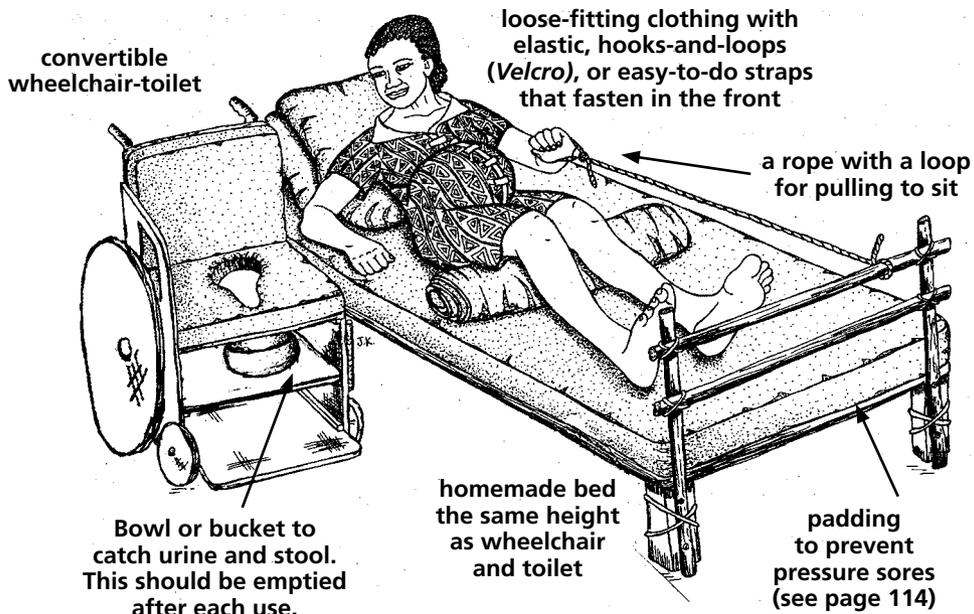
Getting up from a lying down position will be easier if you:



Also, getting up will be easier if you have a heavy chair or box close by to use for support.

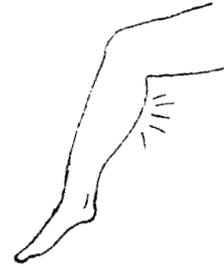


A few simple aids can help many women with physical disabilities during the last weeks of pregnancy when movement is the most difficult.



MUSCLE CRAMPS

These are strong, painful contractions of a muscle, usually in the lower leg, especially at night. If you touch the cramped muscle, it may feel like a hard lump. Leg cramps may be caused by not having enough calcium in the diet.



What to do:

- Do not point the toes—even when stretching.
- Do stretching exercises regularly (see pages 90 to 95).
- Eat more foods with calcium, such as milk, cheese, yogurt, sesame seeds, and green leafy vegetables. Also, eat bananas.
- Sleep on your side with something soft like rolled-up cloth or newspaper between your knees and with your legs slightly bent.
- Do not lie down or sleep under heavy bed covers, and do not tuck covers tightly around your body.

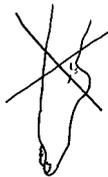


If your foot or leg cramps:

point your
toe up,



not
down,



then stroke
your leg.



Soaking your legs in warm water, or putting a cloth soaked in warm water on the cramping area may also help.

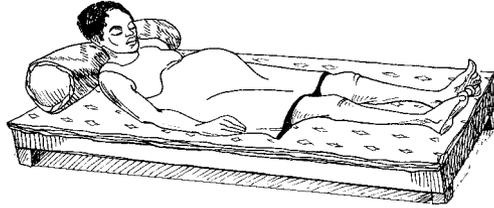
MUSCLE SPASMS

These are tightening or pulling of muscles that make it difficult for a person to control her movements. They happen most often to people with cerebral palsy or a spinal cord injury. Women with these injuries can have muscle spasms during labor (see page 243).

What to do:

- Do not pull or push directly against the tight muscles. This will make them worse.
- Gently hold and support the affected part until the muscle relaxes.

If the back or the whole body is affected by muscle spasms, put something under the head and shoulders to bend them forward a little. This helps to relax stiffness in the whole body.



- Apply warm soaks to the tight muscles or, if possible, sit or lie in warm water. Be careful not to burn the skin or overheat the body, especially if you cannot feel hot or cold things against your skin. Too much heat can cause damage to the unborn baby.
- Gentle stretching exercises done 2 to 3 times each day can help reduce tight muscles.
- Weight-bearing exercise, like standing up, also helps keep muscles strong and reduces muscle tightness.



Sitting in clean, warm water will help muscle spasms relax.

IMPORTANT As a general rule: **Do not massage spastic muscles.** In some countries, people and even therapists use massage or rubbing to relax spastic muscles. Although massage often helps relax muscle cramps, or tight muscles from other causes, in spasticity, massage usually increases the muscle tightness.

BACK PAIN

Most pregnant women, whether or not they have a disability, get back pain, especially in the weeks just before the baby is born when the belly is very big and heavy. Most often this is because the muscles in the belly are stretched and weakened during pregnancy, and the back muscles have to work harder.

Women with some physical disabilities seem to get back pain that is more severe and that happens earlier in the pregnancy. Even women who have no feeling in the lower body often notice back pain while they are pregnant.

What to do:

- Exercise before, during, and after pregnancy to stretch and strengthen the muscles in the lower back and to keep the muscles in the belly strong. Swimming is a good way to reduce back pain and to stay strong.
- Sit in a straight-backed chair.
- Rest, heat, and massage on the painful area can help reduce back pain.

A binder of cloth may help to support your belly so it does not pull so much on your back muscles.

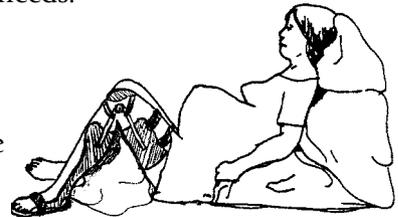
- Wind a piece of clean, thin cotton cloth, about 4 to 5 feet long (1½ meters) around your belly like this.
- Do not wind it so tight that it is uncomfortable.
- You can keep it in place with a safety pin, or you can tuck in the end of the cloth.

**BREATHING DIFFICULTIES**

As the baby grows, it pushes against the mother's lungs and she has less room in her chest to breathe. This is normal in pregnancy. But women with some physical disabilities, such as short stature (dwarfism) or paralysis of the chest muscles, can get short of breath earlier in the pregnancy than other women. The baby gets oxygen from the mother's lungs, so a pregnant woman must keep her lungs clear and healthy for the developing baby to get all the oxygen it needs.

What to do:

- Sleep sitting up a little. You will be more comfortable if you put something under your knees.
- Drink water often, at least 8 glasses a day. This will help mucus in the lungs stay loose so it is easier to cough up. Mucus in the lungs can cause an infection.
- Get regular exercise.
- If you start coughing up phlegm (mucus with pus), see a health worker. You may need to take medicine, like antibiotics. A health worker can help you decide which antibiotic or other medicine is safe to take while you are pregnant.



IMPORTANT If a mother is having difficulty breathing and is also weak and tired, or if she is short of breath all the time, she should see a health worker. She may have heart problems and need medical care. Or she could have anemia (see page 87), a poor diet, an infection, or she may be depressed (see page 54).

ACHES AND PAINS IN THE JOINTS

A pregnant woman's body gets soft and loose to make room for the baby to grow and to get ready to give birth. Sometimes her joints also get loose and uncomfortable, especially the hips. This usually happens during the last few weeks of the pregnancy. It is not dangerous and will get better after the birth.

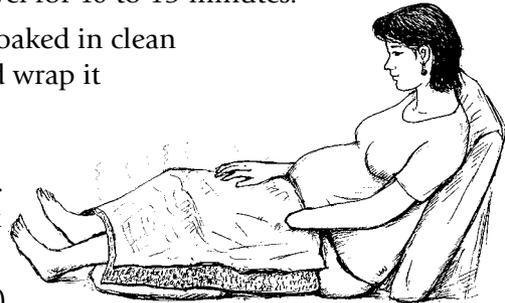
What to do:

- Rest the painful joints. Move a little from time to time so that the joints will not get stiff, but your movements should be gentle.
- Applying cold or heat to the painful joint often reduces pain and makes movement easier. Usually cold works best on hot, inflamed joints, and heat on sore, stiff joints. Experiment to see which works best for you. If you cannot feel hot or cold things against your skin, be careful not to burn or freeze yourself.

For cold: Use ice wrapped in a cloth or towel for 10 to 15 minutes.

For heat: Use a thick cloth that has been soaked in clean hot water (squeeze out the extra water) and wrap it around the sore joint. Cover the cloth with a piece of thin plastic, and wrap with a thick dry cloth or towel to hold in the heat. When the wet cloth starts to get cool, put it back in the hot water and repeat.

Or fill a bottle (ceramic, plastic, or glass) with hot water, close it securely, wrap it in a cloth, and hold it against the painful area.



Heat will help ease sore and stiff joints.

- Take paracetamol (acetaminophen) for pain, 500 mg every 3 to 4 hours. But do not take more than 8 tablets (4000 mg) in 24 hours (see page 350).

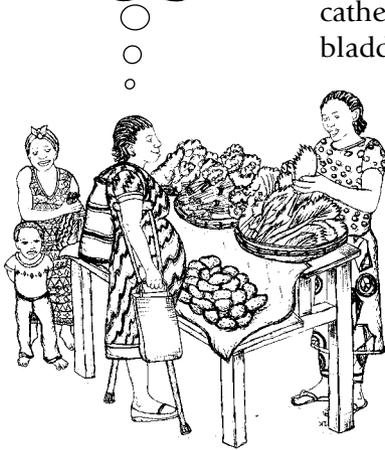
LEAKING URINE

Many women find that as their belly gets bigger, it gets harder to control leaking urine. During pregnancy, women with physical disabilities such as limited muscle control and paralysis or loss of feeling in the lower body often have more problems than other women with leaking urine.

As the baby grows and the mother's belly gets bigger, the baby may push against the bladder, leaving less room for urine. This can make urine leak out at times, especially when the woman coughs or sneezes. Sometimes the urine comes out so suddenly that it is hard to tell if it is urine or if the 'bag of waters' has broken. You may be able to tell by the smell if it urine or not. If this happens, watch for other signs of labor, and ask a health worker or midwife for advice.

If you normally use a catheter each time you want to pass urine, continue to do this if it does not cause you any problems. But if you find it too difficult to put a catheter in more times than usual, try using thick pads of cloth to catch the urine. These pads must be changed, washed and dried often to prevent a rash or an infection on the skin around your genitals (see pages 111 to 113). Make sure the pads are clean and dry before using them again.

I'm doing my squeezing exercise and Ekaete doesn't even know!



Some women change to a catheter that is left in all the time (a 'fixed' or Foley catheter). But, if possible, try not to do this, because it may be difficult to change back after the baby is born. The muscles that control your bladder will "forget" how to hold the urine inside. Also, having a catheter in all the time can increase the risk of getting a bladder infection.

If you have trouble with leaking urine at night, use pads, or keep a bowl, bucket or something else close by to pass urine into. A convertible wheelchair-toilet may be a good solution (see page 224).

If you are able to use the muscles in the lower belly, the squeezing exercise (see page 101) sometimes helps to make the muscles around the bladder stronger. For more information on urine problems, see pages 105 to 106.

DIFFICULTY PASSING STOOL (CONSTIPATION)

Many pregnant women have trouble passing hard stools. Pregnancy can make the bowels work more slowly, and this can make the stool more difficult to pass. See page 108 for information on how to reduce and prevent constipation.

Women who use a 'bowel program' (see page 107) to pass stool may need to remove the stool more often while they are pregnant. Hard stool that is not removed can cause dysreflexia (see pages 117 to 119), which is very dangerous.

WARNING! Pregnant women should not take medicines called **laxatives or purgatives for constipation**. These work by making the bowels tighten or contract—and they may cause labor to start too soon. Some can harm the baby.

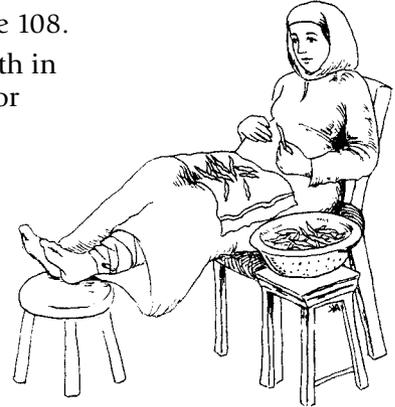
Also, pregnant women should not wash out the bowels with water (enema). This could also start labor too soon.

PILES (HEMORRHOIDS)

Hemorrhoids are swollen veins in and around the anus. They often itch, burn or bleed, and they can be very painful. Hemorrhoids sometimes look like large 'blood blisters.' Straining to pass stool when you are constipated makes them worse. Many women, both disabled and non-disabled, get hemorrhoids while they are pregnant. Sitting for a long time seems to make them worse.

What to do:

- Follow the advice for preventing constipation on page 108.
- To help shrink the hemorrhoids, soak some clean cloth in a drying (astringent) plant juice, such as witch hazel or cactus, and put it on the painful area.
- Use a cushion when sitting to reduce pressure.
- Try to move at least once every hour.
- If you lie down all the time, try to lie on your side, and have someone help you change position regularly.
- Sit or lean back with your feet and legs up. This will help your blood circulate better and heal the hemorrhoid more quickly.

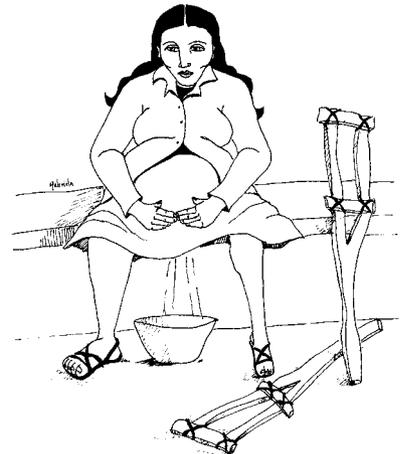


Common health problems

BLADDER INFECTIONS

During pregnancy, all women are more likely to get a bladder infection than at other times. As the womb grows larger, it presses against the bladder and may prevent all the urine from coming out. Germs can grow in the remaining urine and cause an infection.

Women with disabilities, such as limited muscle control, and paralysis or loss of feeling in the lower body, tend to have more problems than other women with leaking urine and infections of the bladder and kidneys. Bladder problems are a common cause of dysreflexia (see pages 117 to 119).



If you usually push on your belly to make urine come out, it is still OK to do this while you are pregnant. You will not harm the baby.

Women who use a “fixed” catheter may find that the urine stops coming out. This can happen if the expanding womb presses on the catheter and stops the urine flow. See a health worker.

If you can take care of a bladder infection right away, you may be able to prevent more serious problems, such as kidney infection and early labor. Watch carefully for signs of infection, and see a health worker if necessary.

To prevent urine infections while you are pregnant:

- drink plenty of water or fruit juices—at least 8 glasses a day.
- keep your genitals clean.
- pass urine after having sex.
- always wash your hands before using a catheter.
- clean your catheter more often (see pages 102 to 104).

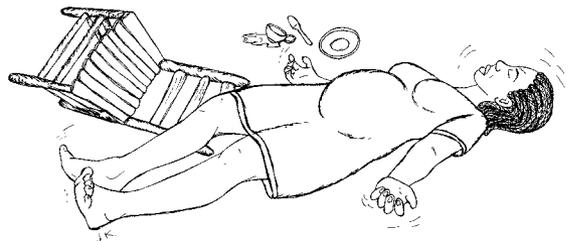


One way to know if you are drinking enough liquid is to try to notice the color of your urine. If it is a dark yellow, you are probably not drinking enough. The urine should be light yellow, almost like water. Drinking lots of tea or coffee will not help because the caffeine in them will make you lose more fluid than you drink.

For more information on bladder and kidney infections, see pages 105 to 106.

SEIZURES (CONVULSIONS, “FITS,” EPILEPSY)

It is hard to say whether a woman who has epilepsy will have more or fewer seizures while she is pregnant. If you are someone who gets seizures, you will know best how often you get them and how severe they are. Some antiseizure medicines, especially phenytoin (diphenylhydantoin, *Dilantin*), may increase the risk of birth defects when taken by a pregnant woman. But do not stop taking anti-seizure medicines while you are pregnant. This can make seizures worse and may even kill you. Talk with an experienced health worker or doctor who understands epilepsy and can help you decide about the best medicine to take. Phenobarbital (phenobarbitone, *Luminal*) is probably the safest anti-seizure medicine to take during pregnancy.



TOXEMIA OF PREGNANCY (PRE-ECLAMPSIA)

Some swelling in the legs and ankles is normal in pregnancy. But swelling of the hands and face can be a sign of pre-eclampsia (also called toxemia of pregnancy), especially if you also have headaches, blurred vision, or pains in your belly. Sudden weight gain, high blood pressure, and a lot of protein in the urine are also signs of toxemia. Toxemia can cause convulsions (seizures or ‘fits’), and both you and the baby can die. Convulsions are different from the seizures caused by epilepsy (see page 231).

You may be at risk of toxemia if you or your mother or sisters have had it, or if it is your first pregnancy, or you are pregnant for the first time by a new partner. Toxemia is also more common for women who have high blood pressure, diabetes, kidney problems, for severe headaches, for women over 35, and for women expecting more than one baby.

If you have any signs of toxemia, go to a midwife or healthworker who can test you to see if you are in danger.



What to do:

- Stay quiet and in bed. Eat good, nutritious foods, especially foods rich in protein, but with only a little salt. Avoid salty foods.
- **If you do not get better quickly**, or if you have trouble seeing, or the swelling increases in your face, or if you have a seizure, **get medical help fast**. Your life is in danger.

PRESSURE SORES (BED SORES)

Women who sit or lie down most of the time can develop pressure sores easily if too much time passes without moving or changing position. This is especially true for women who are paralyzed and cannot feel pain. When you are pregnant, the extra weight puts even more pressure on the body parts where sores are the most likely to develop.

What to do:

Try to move or change your position more often than usual—at least once every hour. Check your skin over the pressure-sore areas more often than before you were pregnant. Also, see page 116 for information on preventing pressure sores.

HIV/AIDS and pregnancy

Although there is still no cure for HIV/AIDS, there are medicines that can help people with HIV/AIDS live much longer. They are the same medicines (called ARVs) that help prevent a pregnant woman from passing HIV to her baby during pregnancy, at birth, or while breastfeeding (see pages 358 to 362).

If you have HIV and you are pregnant, it is important for you to get treated for your disease as well as getting normal care for your pregnancy. Women who are infected with HIV can have more problems in their pregnancies, such as:

- miscarriage.
- fevers and infections.
- yeast infections of the vagina, mouth, or stomach.
- sexually transmitted infections.
- problems after the birth, such as bleeding and infection.

Try to find out if medicine is available to treat you, to prevent your baby from getting HIV, or to treat the baby early. If there is a well-equipped medical center in your area, it may be better for you to give birth there.

Working for change

What families and caregivers can do:

- Help us get enough food and rest.
- Be positive about the pregnancy.
- Make sure we get prenatal care and go with us to get exams.
- Be of assistance any time.



Women with disabilities have much the same concerns as other women who are pregnant. We want to have a healthy pregnancy and give birth to a healthy baby.

What midwives, doctors, and other health workers can do:

Health workers will be able to help us if we start going to see them early in our pregnancy, or even before we are pregnant. Because very few doctors, nurses, midwives, and other health workers have experience caring for women with disabilities, we can help them learn what is natural for us and how our disabilities may (or may not) affect pregnancy. Health workers can also:

- learn about possible problems a woman with a disability may (or may not) have during pregnancy.

- be aware of things we can do. For example, do not assume we cannot have a vaginal birth. Remember, that just because a woman may have a disability, it does not mean her womb is damaged. Even if her body and legs are paralyzed, her womb will still be able to contract and push out a baby.
- organize a group for women with disabilities for advice on eating well, medicines and health exams during pregnancy.
- make sure we have easy-to-use health care during pregnancy.

Women with disabilities improve health access in Uganda

The Disabled Women's Network and Resource Organization in Uganda (DWNRO) works to help health professionals become more aware of the needs of women with disabilities. Their main concerns are accessibility, availability, and attitude. For example, when pregnant women with disabilities are treated poorly by hospital staff, they lose self-confidence and do not go back for prenatal care. They can have problems with the pregnancy later, or with the birth, that could have been prevented with regular checkups.

The DWNRO held regional workshops for doctors and midwives on the lack of access to hospital wards and services, such as postnatal care, weighing scales, exam tables, and adequate communication with deaf and blind women. Some hospitals have made wards more accessible, and a deaf women's group recently trained a groups of midwives in sign language. The DWNRO is now working to make women with disabilities aware of these services so they will demand them.

