

**PREGNANCY AND DELIVERY
IN WOMEN WITH
SPINAL CORD DISORDERS**

Editor
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NATIONAL REHABILITATION CENTER
FOR PERSONS WITH DISABILITIES
JAPAN

(WHO COLLABORATING CENTRE)

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- 2 To develop technologies for improvement of social skills and promotion of economical independence in collaboration with PWDs.
- 3 To study and develop social systems for PWDs such as primary health care, social care, etc., in the community.
- 4 To research and develop affordable assistive products and its service in collaboration with PWDs.
- 5 To prepare manuals for education and training of professionals in health, medical and welfare services for PWDs.
- 6 To conduct training programs, conferences and /or seminars on rehabilitation of PWDs for dissemination of technologies and information.

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Pregnancy and Delivery in Women with Spinal Cord Disorders

February 27, 2009

Editor: Fumio ETO

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PREFACE

Among the activities of physically-disabled persons in their daily lives, their sexual activities seem to be mentioned less frequently in Japan than in Western countries. The difference in cultural background can be considered as one of the causative factors. In the natural course of sexual activities, women become pregnant and experience delivery. There are few guidebooks that provide handicapped persons with information about childbirth and child-care related activities. Of physical disorders, spinal cord disorders is frequently accompanied by disorders of urination and defecation and disturbance of sensation as well as limb movement disorder, and special care is required in patients with these disorders in daily life during pregnancy. Even in such situations, many female patients with spinal cord disorders have actually experienced delivery in Japan.

Recently, we requested women who suffered spinal cord disorders and went through delivery to provide their own opinions about the problems related to their delivery and child-care, and helped the Japan Spinal Cord Foundation organize and publish the information obtained in the form of a book titled "I Can Be a Mother." Through such experiences, we prepared this manual containing information about physical symptoms that often occur during pregnancy, points to be considered in daily life during pregnancy, methods of delivery, preparation for having a baby, and tips for child-care.

Because there is insufficient information about pregnancy and delivery that serves for women suffering from spinal cord disorder, even medical professionals may have misunderstandings. We hope that this manual is utilized by women with spinal cord disorder who wish to have babies but are very concerned about pregnancy and delivery, their partners and families, and the medical care and welfare providers, as well as contributing broadening their futures.

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CONTENTS

Preface

Contributors

Introduction 1

Chapter 1.

The Biology of a Woman's Body 2

1. Menstruation 2

2. Pregnancy 2

3. Sexual Activities 2

4. Family Planning 3

Chapter 2.

Before Getting Pregnant 4

1. Physical Healthcare 4

2. Finding Helpers 6

3. Others 6

Chapter 3.

Learning of Pregnancy 7

1. Signs of Pregnancy 7

2. Pregnancy Test Kits 7

3. Selection of Maternity Hospitals 7

4. Initial Consultation 8

Chapter 4.

Points to Be Considered during the Early Gestation Period (0 to 15th week) 10

1. Trouble You May Encounter during the Early Gestation Period
and Countermeasures 10

2. Points to Be Considered in Daily Activities during the Early Gestation Period 13

3. Maternal and Child Health Handbook 13

Chapter 5.

Points to Be Considered during the Mid-pregnancy Period (16th to 27th week) 15

1. Issues Occurring during the Mid-pregnancy Period and Countermeasures 15

2. Tips for Preparing for Delivery 17

Chapter 6.	
Points to Be Considered in the Late Pregnancy Period (after the 28th week).....	20
1. Problems Frequently Encountered in the Late Pregnancy Period	20
2. Points to Be Considered in Daily Life during the Late Pregnancy Period	22
Chapter 7.	
Signs Indicating Initiation of Delivery	25
1. Signs of delivery.....	25
2. Signs requiring immediate medical attention.....	25
3. What is labor pain	25
Chapter 8.	
Delivery	26
1. Problems that May Be Encountered during Delivery	26
2. After Delivery.....	26
Chapter 9.	
Taking Care of Your Baby	28
1. Breastfeeding	28
2. Changing Diapers/clothes	29
3. Bathing	30
4. Playing	31
5. Taking a Walk	32
6. Others	32
Chapter 10.	
Voices of Women with Spinal Cord Disorders Who Have Experienced Delivery.....	33
1. During Pregnancy	33
2. Voice of Experience	34
3. Message from mother to children.....	34
Cited Literature	36
References	37

Introduction

It is natural for women to hope to have a baby. At the same time, however, there is some anxiety about possible risks relating to child delivery and care. Because only a few cases of pregnancy and parturition in women with spinal cord disorders* have been reported in Japan, details of such cases remain unknown and may lead to some misunderstanding.

On the basis of the experiences of women who have suffered spinal cord disorders and gone through delivery, this manual intended to provide information about the physical changes that take place during pregnancy, precautions for pregnant women, and tips for child-care. It may be hard for handicapped women to have a baby and take care of their children, but the presence of such women who actually experienced delivery and child-care may greatly encourage those who will have babies in the near future.

It is important for couples to carefully consider pregnancy, delivery and child-care. We hope that women with spinal cord disorders have thorough discussions with their husband about having a baby and read this manual if they wish to have children. We also recommend women who have not yet decided to have babies, people with disabilities, their families and those engaged in healthcare and welfare to read this manual so that they can understand delivery and child-care in women with spinal cord disorders.



Footnote

* Spinal cord disorders

Damage to the spinal cord resulting from any type of injury or underlying disease. Spinal cord disorders are associated with the paralysis of motor and sensory functions.

Chapter 1.

The Biology of a Woman's Body

Female sexual functions are greatly affected by female hormones. However, female hormones have no influence on spinal cord disorders. Therefore, spinal cord disorders do not seriously affect menstruation and pregnancy.

1. Menstruation

Menstruation plays an important role as an indicator of health in women. Therefore, feelings of sickness and shocking events may disrupt a menstrual cycle. Women with spinal cord injuries may occasionally experience disruption of menstruation after suffering an accident or a disease. Menses resume spontaneously in most cases, but some patients may complain of prolonged cessation of menses. The results of our survey¹⁾ have shown that the majority of patients experienced resumption of menses within six months after injury, but some patients suffered amenorrhea for one to five years or even more than five years. Prolonged amenorrhea may lead to difficulty in achieving pregnancy or development of osteoporosis. Women who do not have menses for more than three months are advised to consult an obstetrician.

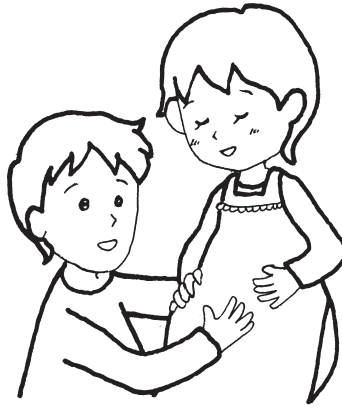
2. Pregnancy

Spinal cord disorders have no direct effect on pregnancy. During pregnancy, however, care should be exercised to prevent urinary tract infection, anemia and autonomic hyperreflexia^{*2-16)}.

3. Sexual Activities

Women with spinal cord disorder can have a satisfactory sexual life. Those with impaired excretion* may experience urinary or fecal incontinence during sexual activities. A woman with severe foot spasm* may kick her partner and find it difficult to open her legs smoothly. If effective measures are taken in advance, problems can be reduced¹⁷⁻¹⁹⁾. The intensity of orgasmic sensation differs from individual to individual, but many people feel fulfilled through repeated experience.

The relationship with your partner is an essential part of your sexual life. Keeping a good mutual relationship is of prime importance.



4. Family Planning

A couple can voluntarily determine when they have a baby and how many babies they are going to have. However, it is important that they assume responsibility for their coming baby. It is important for women to be pregnant in an ideal environment. For this reason, they are advised to use a reliable contraceptive method when they do not wish to be pregnant.

☆ People who may be allergic to latex are recommended to use latex-free condoms.



Footnotes

* Autonomic hyperreflexia

Autonomic hyperreflexia is an excessive reaction to harmful stimulations that are less severe than an injury, such as an accumulation of urine/feces and minor physical wounds, as well as examination- or treatment-related stimulations. The following symptoms are observed: sweating, headache, increased blood pressure, and facial flush. Patients with injury of the 6th thoracic cord or above may suffer more frequently from autonomic hyperreflexia.

* Impaired excretion (dysuria and dyschezia)

Dysuria is defined as a condition characterized by impairment in the storage of urine in the bladder or release of urine from the bladder.

The symptoms of dysuria include urinary retention (anuresis), difficulty in urination, frequent need to urinate (pollakiuria) and urinary incontinence.

Dyschezia is defined as a condition characterized by abnormal functions of the large intestine and anus. The symptoms of dyschezia include constipation, diarrhea, and fecal incontinence.

* Spasm

Spasm is defined as a condition characterized by an inward or outward twist of the feet, hands, and fingers and their flexion or extension due to excessive muscle tone. Spasm is induced by diseases such as cerebral palsy and stroke, as well as spinal cord injuries, which may disturb the signals from the nerves that control muscles and induce spasm.

Chapter 2. Before Getting Pregnant

1. Physical Healthcare

Many women worry about drugs and radiation to which they are exposed before becoming pregnant. When you start to think about becoming pregnant, you are advised to consult with your physician about the medications and radiological examinations you are to receive.

1) Medications

A common method of calculating gestational age is to start counting from the first day of the woman's last menstrual period ("Day 0, Week 0"). Drugs taken during the period from Day 0 to Day 27 (the period from the time before conception to the end of the 3rd week of pregnancy) have few adverse effects on pregnancy. However, drugs taken during the period from Day 28 to Day 50 (the period from the 4th week to the end of the 7th week of pregnancy) may have serious effects on pregnancy because the central nervous system and important organs including the heart of the fetus are formed during this period. Formation of the fetal organs is nearly completed at the 16th week of pregnancy and later. Therefore, the risk of deformation decreases during this period, but the possibility of adverse effects on functional development remains.

The following drugs are commonly used in patients with spinal cord disorders: analgesics, antibiotics for urinary tract infection, anticholinergic agents for pollakiuria and urinary incontinence, antispasm drugs/antispasmodics, anticoagulants, laxatives, enemas/suppositories for stimulation of defecation. If you stop taking such prescribed drugs on your own judgment, you may experience aggravation of symptoms. It is important for you to consult with your physician about the use of medications.

2) Radiological Examination

Radiological examination is rarely indicated in pregnant women; however, it often happens that a woman is exposed to radiation before finding herself pregnant. Although ordinary X-ray examinations may have few effects on pregnancy, pregnant women are recommended to avoid such examinations whenever possible. Therefore, women with spinal cord disorders are advised to consult with their physicians about any necessary examinations before getting pregnant.



3) Excretion

Pregnant women often complain of constipation. If a proper diet and sufficient physical exercise do not help to relieve constipation, you may choose to use laxatives. Patients with difficult bowel movement often use laxatives or suppositories and encourage defecation by pushing the abdomen. This method, however, should be avoided whenever possible in pregnant women. They are advised to take dietary fibers and oligosaccharide to improve constipation.

4) Urination

Women with dysuria are vulnerable to cystitis, pyelonephritis* and hydronephrosis*.

Women under self-catheterization* are advised to check if they store excessive urine in the bladder or if catheterization is done at regular intervals. Cystoplasty and urinary diversion may result in dislocation, deformation or adhesion of the intestine, bladder, uterine or ovary. Because these conditions may affect Caesarean delivery, women with spinal cord disorder are advised to consult their physicians in advance.

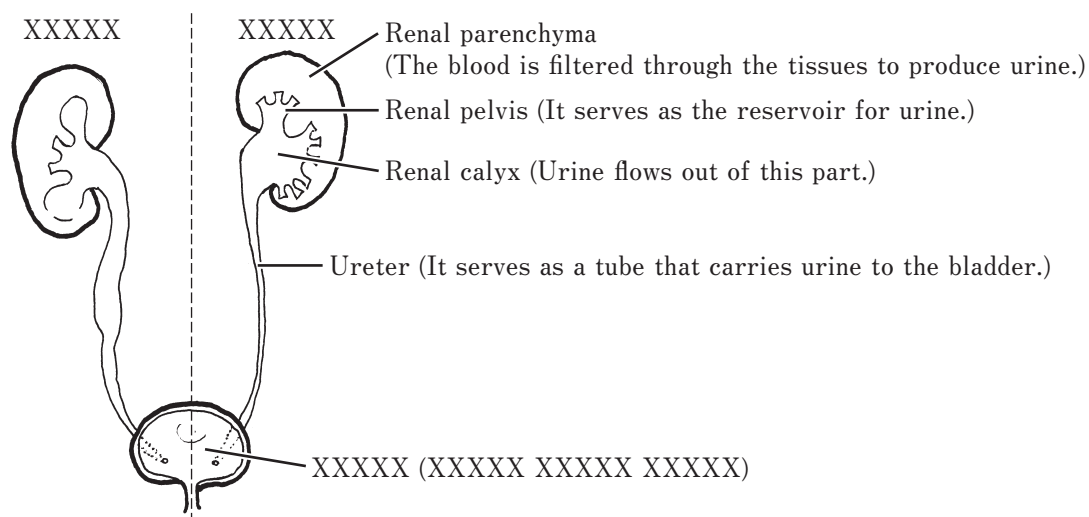


Fig. 1 Bladder, ureter, and kidney

Footnotes

*Pyelonephritis

Pyelonephritis is an inflammatory disease of the renal calyces and pelvis due to local bacterial infection. Clinical symptoms include fever, nausea, and cloudiness of urine with blood and pus.

*Hydronephrosis

This is a condition associated with dilation of the pelvis and calices together with atrophy of the renal parenchyma, resulting from obstruction of the urinary tract, a pathway for urine produced in the kidneys. The causes of urinary tract dilation include interruption of the flow of urine due to the presence of calculi, and vesicoureteral reflux, a phenomenon characterized by the backward flow of urine from the bladder into the ureter.

*Self-catheterization

Patients with dysuria can empty the bladder themselves by discharging urine stored in it using a catheter (a special thin tube) several times a day. This treatment is important to prevent urinary tract infection. Incomplete excretion with residual urine in the bladder may result in continuous proliferation of bacteria in the urine. Therefore, cystitis may not be improved.

5) Intake of Folic Acid

Recently, pregnant women are recommended to take folic acid because lack of folic acid during the early gestation period may increase the risk of delivery of babies with impairment of the nervous system. According to the 2005 Japanese Standards for Dietary Intake, the Ministry of Health, Labour and Welfare also recommends pregnant women to take 440 μ g of folic acid. Folic acid is needed during the early gestation period because cell division is highly promoted in this period. It is said that insufficient intake of folic acid in this period may increase the risk of development of anencephaly and diseases resulting from neural tube closure defects. As women usually notice that they are pregnant after this period is over, it is advised to start taking folic acid more than one month before getting pregnant.

The amount of folic acid may be insufficient by means of dietary intake only. Because folic acid is easily destroyed by heat and its absorption rate is low, supplements and fortified food containing the nutrient are recommended to be used in combination with a regular diet.

6) Others

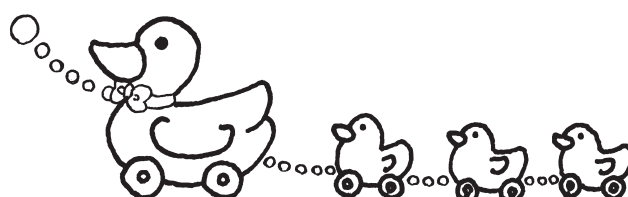
Women with spinal cord disorder may suffer pelvic fracture, lateral spinal curvature, and decreased respiratory function. These pathological conditions may adversely affect fetal development and the mother's daily activities during pregnancy. Such conditions are also important information to determine the delivery method. Women are recommended to understand their own physical conditions.

2. Finding Helpers

During pregnancy, women may feel sick for several days or be unable to do things as usual. You will probably feel relieved if you have some reliable persons whom you can ask to do housework. Once you have your baby, you may find it difficult to get used to taking care of a child by yourself. The presence of helpers may be a form of practical support; therefore, it should be confirmed in advance whether any family members, caregivers, and volunteers can support the care of your child.

3. Others

Remodeling of rooms and arrangement of work should be discussed with your family members and colleagues in advance.



Chapter 3.

Learning of Pregnancy

When becoming pregnant, various signs including failure to menstruate are noted. If you notice any signs of pregnancy, you should consult an obstetrician as soon as possible as you may need to inform your family members, supervisors, and other people of your pregnancy.

1. Signs of Pregnancy

Women usually notice they are pregnant when they discover a delay in menstruation. If you have a regular menstruation cycle but your period is late by more than one week, you are likely to be pregnant. Pregnant women may feel hot and tired, become sleepy most of the time, notice an engorgement and stiffening of the breasts, have tenderness of the breasts, feel nauseous, and recognize a change of food preference.

2. Pregnancy Test Kits

Commercially available pregnancy test kits are so sensitive that they are able to detect pregnancy even a few days after the scheduled menstrual period. They are easy to use but the results serve only as reference. If your pregnancy test is positive, you should consult an obstetrician immediately.

3. Selection of Maternity Hospitals

Pregnant women usually undergo delivery in the hospital where they received initial consultations. Therefore, it is important to select an appropriate hospital at the initial stage.

You can give birth in the following medical institutions: university hospitals, general hospitals, maternity hospitals, private hospitals and maternity centers. Women with spinal cord disorders are recommended to visit a university hospital or general hospital, which are equipped with sufficient medical staff and provide relatively advanced medical care.

[Tips for Selecting Hospitals]

1) Easy Access

Generally, pregnant women need to consult an obstetrician once a month until the 27th gestation week, twice a month from the 28th to the 35th gestation week, and once a week from the 36th gestation week.

Pregnant women with spinal cord disorders are likely to see an obstetrician more frequently. In view of the possibility of an emergency visit, it is preferable to select a hospital easily accessible from the patient's home within one hour.

2) Facilities

Pregnant women with spinal cord disorders should consider whether the hospital is accessible for wheelchairs as well as whether it is equipped with sufficient medical facilities, according to the following points:

- a. A parking lot for handicapped persons is available.
- b. There is no difference in the level of the passage from the parking lot to the reception desk, or there is a slope.
- c. A patient can go into the doctor's office using a wheelchair.
- d. Rest rooms for handicapped persons are available.
- e. Scales for disabled persons are available.

3) Variety of Treatment Departments

In view of the increased risk of urinary tract infection and the possibility of complications of pyelonephritis and hydronephrosis during pregnancy, women with spinal cord disorders should select a hospital which has a department specializing in urination management. Also, your concern about delivery may be reduced if the hospital has departments of urology, anesthesiology, pediatrics and rehabilitation.

☆ It may be hard to find a hospital that meets all the above requirements, but it is important to ask hospitals first if you can receive examinations and treatment there.

4. Initial Consultation

If you have regular menstruation but your period is late for one or two weeks, it is time for you to consult an obstetrician.

Because pregnancy is not a pathological condition, the necessary medical expense is not covered by the health insurance. However, you should take your health insurance certificate when you visit a hospital.

1) Questionnaire

The responses to the questionnaire are to be used as reference material on the initial consultation. Therefore, detailed information about your condition, including spinal cord disorders, should be provided in the questionnaire form.

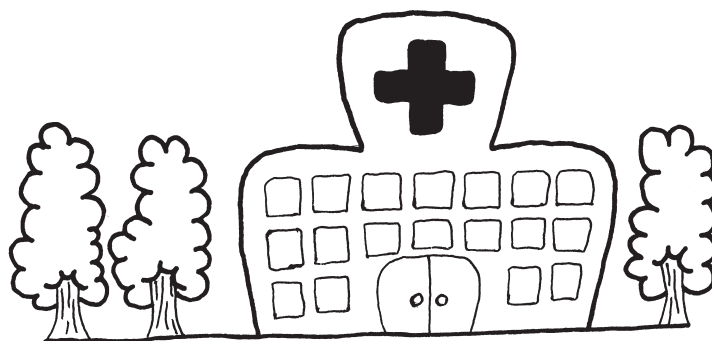
2) Pelvic Examination

On the initial consultation, you undergo urinalysis, blood pressure measurement and finally a pelvic examination. A pregnant woman is usually asked to sit on the special chair during a pelvic examination. Generally, the special chair is placed in a narrow space and a wheelchair cannot be brought alongside the special chair. The nurse or physician may help you sit on the special chair or ask you to lie down on the

ordinary examination table and open your legs. A skirt is more convenient for pelvic examination because you only remove your underwear before the examination.

3) Diagnosis of Pregnancy

Ultrasonography shows the fetal sac at the 6th gestation week, the fetus at the 7th to 8th gestation week, and the fetal heart movement at the 7th to 9th gestation week. In transvaginal ultrasonography, a probe is inserted into the vagina to visualize the fetal heart movement at the 5th to 6th gestation week.



Chapter 4.

Points to Be Considered during the Early Gestation Period (0 to 15th week)

During the early gestation period, few people will notice your pregnancy as you are not so large with child. In the womb, however, the baby is growing rapidly. You may experience a hormone imbalance and notice the beginning of morning sickness. You may feel ill for several days and may be conscious of trivial matters, but you should try to avoid becoming overly nervous.

I. Trouble You May Encounter during the Early Gestation Period and Countermeasures

1) Threatened Abortion

A threatened abortion is a condition that suggests a miscarriage might take place.

(1) Signs of a threatened abortion

a. Bleeding

* Bleeding often continues incessantly, and conditions vary widely from spotting to massive hemorrhage.

b. Lower abdominal pain

c. Others

Headache, chest pain, cold sweats, enhanced spasm, autonomic hyperreflexia, etc.

☆ If emergency treatment is introduced immediately, miscarriage can be prevented in some patients even with these signs.

(2) Treatment

Bed rest is recommended. Hospitalization may be required depending on the patient's condition.

2) Miscarriage

Pregnancy ends if the fetus comes out of the mother before the 22nd gestation week. Such a spontaneous end of pregnancy is defined as miscarriage. The definite causes of miscarriage remain unknown in most cases, but problems associated with the fetus accounts for 50 to 60% of all causes.

3) Anemia

As the baby grows, the maternal blood volume increases. The red blood cells, however, do not increase proportionately, leading to an anemic condition. Both the fetus and the mother need iron to produce blood, which results in a deficiency of iron in the blood of the mother. Anemia causes autonomic instability leading to dizziness and hypotension. In patients with spinal cord injuries, these symptoms increase in

severity. Care should be exercised not to fall out of your wheelchair if you have such symptoms.

Anemia can be detected based on blood test results. Therefore, if you notice any anemic symptoms such as fatigue, difficulty in breathing, feelings of discomfort, and dizziness, you are advised to consult your physician to receive blood tests.

If you find it difficult to go shopping and prepare meals, you need to ask your family members or helpers for support. You can also use catering services.

☆ In patients with spinal cord injuries, intake of iron preparations is occasionally ineffective in improving anemia. In such cases, anemia may continue until the time of delivery. Anemia can be managed as it is gradually improved after delivery.

4) Frequent Urination/urinary Incontinence

During the early gestation period, the uterus may rapidly enlarge and compress the bladder. For this reason, you may feel a constant urge to urinate or experience urinary incontinence more frequently. During pregnancy, your underwear may be soiled when you move from the wheelchair to the bed or just sneeze or cough.

[Countermeasures]

- a. Go to the restroom whenever you have a desire to urinate, even if the intervals are rather short.
- b. Those under self-catheterization are advised to increase the frequency of catheterization.
- c. Refrain from taking beverages that contain sugar or caffeine.
- d. Do not consume alcohol.
- e. Use incontinence pads to control urine leakage.
 - * Use of sanitary napkins cannot effectively control urine leakage or odor because their absorption is limited.
- f. Urinary incontinence is occasionally associated with urinary tract infection. Consult your physician if you notice cloudiness of the urine or an offensive odor.

5) Urinary Tract Infection

During pregnancy, the uterus compresses the kidneys, bladder and ureter, which often leads to blockage of urine flow and urinary tract infection. Because urinary tract infection increases the risk of preterm delivery and premature rupture of the membrane, it should be appropriately treated. Clinical symptoms of urinary tract infection include cloudiness of urine, frequent urination, urinary incontinence, hematuria, fever, headache, and nausea. In the event of chills and fever with temperatures above 38.5°C in addition to cloudiness of urine, the possibility of acute

pyelonephritis should be considered. Because the entire urinary system including the kidneys may be infected, immediate consultation with your physician is recommended.

Women with spinal cord disorders are susceptible to urinary tract infection and should exercise caution.

[Countermeasures]

- a. Patients under self-catheterization are advised not to retain too much urine in the bladder. The urine volume collected per catheterization should be less than 200 ml.
- b. Even if there is an increase in urine leakage, water intake should not be reduced and the frequency of catheterization should be increased.
- c. Use of a bidet and cleaning bottles is recommended to keep the vulva clean.
- d. Women who suffer spinal cord disorders but can urinate spontaneously often retain urine in the bladder during pregnancy. The increase in residual urine may cause infection. In this case, self-catheterization may be introduced during pregnancy. Once you become large with child, you may find it difficult to get used to self-catheterization. Therefore, early initiation of training for self-catheterization is recommended.

6) Autonomic Hyperreflexia

Women who have experienced autonomic hyperreflexia (e.g., sweating, facial flush, headache, and elevation of blood pressure) may suffer severer symptoms during pregnancy. Enlargement of the belly or movement of the baby in the belly may induce such symptoms of autonomic hyperreflexia. Autonomic hyperreflexia may also occur during a pelvic examination.

Bed rest in the lateral position is recommended to alleviate painful symptoms. If the symptoms do not improve, consult your physician.

7) Vaginal Infection

Women with spinal cord disorders are vulnerable to vaginal infection²⁰). It is important for them to prevent vaginal infection during pregnancy because it may cause premature delivery or early rupture of the membranes.

[Countermeasures]

- a. If you notice the signs of infection, including increased vaginal discharge, whitish or yellowish vaginal discharge, and an offensive odor, consult your physician.
- b. Use of a bidet is recommended to keep the vulva clean.
- c. Change the pads for vaginal discharge frequently.
- d. Do not wear tight underwear or pantyhose to prevent the skin surface from

becoming sweaty.

- e. Do not sit in a wheelchair for a long time.
- f. Do not wash the vagina. Do not use a portable bidet, which is available at pharmacies without careful consideration.

8) Constipation

Pregnant women often experience constipation more frequently because female hormones adversely affect bowel movement during pregnancy. Most patients with spinal cord disorders use laxatives or suppositories for defecation; however, most women refrain from using such drugs and pushing the belly with the hands during pregnancy, and they often have aggravation of constipation. Persistent constipation may cause nausea, prolapse of the anus and hemorrhoids.

[Countermeasures]

- a. Ensure you get good sleep. Bowel movement is improved during sleep.
- b. Try to relax. Stress may aggravate bowel movement.
- c. Increase your intake of oligosaccharide and dietary fibers, which soften stools.
- d. Go to the restroom regularly.
- e. Pushing the belly with the hands to facilitate defecation rarely causes problems during pregnancy.
- f. Consult with your physician before you use any medications.

2. Points to Be Considered in Daily Activities during the Early Gestation Period

If you feel well, you can do housework as usual. If you suffer morning sickness and feel ill, you can omit some housework.

1) Driving

Refrain from driving because attentiveness is diminished during the early gestation period.

2) Travel and Physical Exercise

Refrain from traveling and physical exercise until your pregnancy enters a stable period.

3. Maternal and Child Health Handbook

It is important to record your health condition in a maternal and child health handbook, which helps in the health management of the mother and the baby. The handbook also serves as the record of the progress of pregnancy because the results of

regular examinations can be recorded in it. Whenever leaving home, pregnant women are recommended to carry the handbook in case of emergency.

Furthermore, the handbook also contains the important records from the time of conception of the mother to the time before the child starts to attend school, including the state of delivery, the baby's condition, results of subsequent health checkups, and prophylactic vaccinations.

The handbook provides useful information about services available in the local community.



Chapter 5.

Points to Be Considered during the Mid-pregnancy Period (16th to 27th week)

During this period, symptoms of morning sickness subside and the pregnancy state becomes stable. The mother can actually recognize the development of her baby.

1. Issues Occurring during the Mid-pregnancy Period and Countermeasures

1) Overweight

During pregnancy, the mother gains weight as a result of the baby's growth and increase in and difficult delivery. Therefore, weight gain should be limited to less than 10 kg.

[Countermeasures]

- a. Check your body weight regularly. You can control weight gain by accurately measuring your weight.
- b. Increase your physical activities as much as possible.
- c. Prepare food with light flavors because food with standard flavors stimulate appetite and increase water intake.
- d. Restrict carbohydrates and snacks but take a sufficient amount proteins and minerals sufficiently.

2) Pregnancy-induced Hypertension

Pregnancy-induced hypertension, which is regarded as a rejection in the maternal body, adversely affects the mother and her baby. A diagnosis of pregnancy-induced hypertension is made if hypertension lasts for the period from the 20th week of pregnancy to the 12th week after parturition, or if hypertension accompanies proteinuria.

Hypertension may be associated with impaired renal function and deterioration of fetal development. Pregnant women with nephropathy, hypertension, and heart diseases, as well as those at risk for obesity, should exercise caution as this syndrome is more likely to be induced by pregnancy in such patients. Aggravation of the symptoms may result in a general convulsive attack. If the mother and her baby fall into a critical condition, an emergency Caesarean section may be necessary.

[Symptoms associated with pregnancy-induced hypertension]

- a. Pregnancy-induced hypertension is associated with few subjective symptoms.
- b. In patients with pregnancy-induced hypertension, an increase in body weight by more than 500 g per week, high blood pressure, and proteinuria are usually

observed in regular check-ups.

- ☆ Patients with spinal cord disorders are likely to have low blood pressure with a systolic blood pressure of 70 to 90 mmHg. A diagnosis of hypertension should be made in these patients based on the above blood pressure range. Because they may also have edema in the lower extremities, they are recommended to undergo blood pressure measurements regularly.

[Countermeasures]

- a. Control your body weight appropriately. Weight gain of more than 500 g per week may increase the risk of pregnancy-induced hypertension.
- b. Take care not to take an excessive amount of salt.
- c. Keep a regular lifestyle.
- d. Have sufficient rest.

3) Edema in the Lower Extremities

Many patients with spinal cord disorders suffer edema, which should be identified to be either lower-extremity edema associated with pregnancy-induced hypertension, ordinary edema of a nonproblematic nature, or a sign of deep venous thromboembolism.

[Countermeasures]

- a. Ask medical staff to measure the perimeter of the lower leg in the prenatal checkup.
- b. Discuss with your physician about the use of elastic stockings and massage.

4) Pressure Ulcer*

As you become large with child, it may be difficult to push yourself up in the wheelchair or to change position on a bed. Such difficulty in turning positions may result in the formation of a pressure ulcer.

[Areas of predilection for pressure ulcers]

Greater trochanter, ischial region, sacral region, sole, etc.

[Countermeasures]

- a. Check your body as often as you can every day.
- b. If you find an area of the skin of the hips that is red, take care not to compress that area.
- c. Give more attention to changing your positions while lying in bed.

- d. Do a push-up in the wheelchair once every 30 to 60 minutes.
 - ☆ You can also reduce pressure on the hips by arching your back.
- e. Check the pressure of your wheelchair cushion.

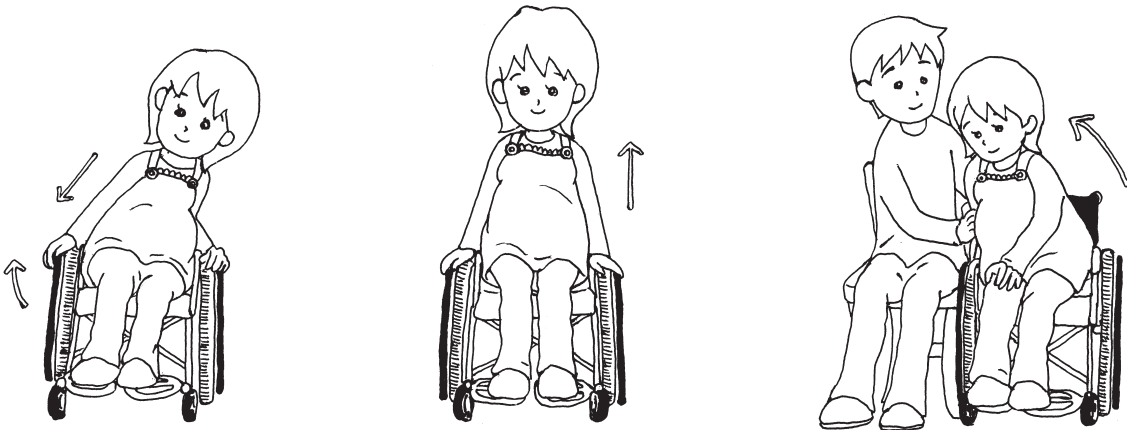


Fig. 2 How to reduce pressure in the wheelchair

Footnote

* Pressure ulcer

When an external force (i.e., pressure or friction) continuously stimulates a given part of the body, the skin or deeper tissues may break down and form a pressure ulcer. Pressure ulcers are frequently formed at the sites where bones protrude, such as the sacral region, ischial region, coccygeal region, greater trochanter, iliac region and calcaneal region.

2. Tips for Preparing for Delivery

Pregnant women with spinal cord disorders may enter hospital earlier than ordinary women in order to assure safe delivery. When your pregnancy enters a stable period, you should make adequate preparations to cope well with urgent hospitalization.

1) Preparation for Hospitalization

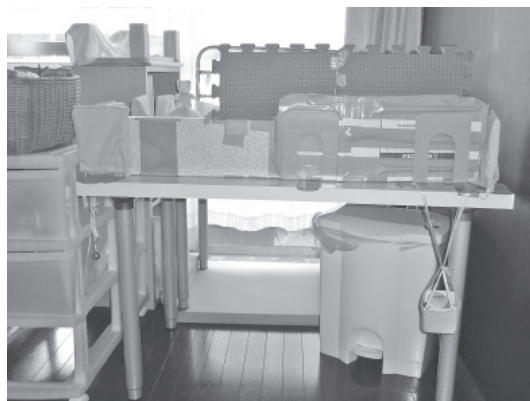
The items needed for hospitalization should be kept in a specified place so that you can bring them to the hospital in case of emergency. You may need to go to the hospital while your family members are out. In view of such a possibility, you should check who can accompany you to the hospital and the means of transportation in such circumstance.

Because the items needed for hospitalization differ from hospital to hospital, you should check them as soon as possible.

2) Preparation for Nursery Items

Prepare the minimum nursery items that you need immediately after childbirth. Remodel the rooms to facilitate childcare.

- a. Crib: You can take care of your baby in a crib if you remodel it into a wheelchair-accessible bed.



- b. Portable bathtub: Use of a nonslip portable bathtub is recommended.



c. Baby sling: A baby sling enables the mother in the wheelchair to carry her baby.



Left fig. The mother can carry her baby with a baby sling.

Right fig. A baby sling

d. Others: Baby chair, etc.



3) Child-care Training

You start to take care of your baby shortly after his/her birth. It takes some time for you to get used to feeding and changing diapers in a wheelchair. Women who cannot use their hands smoothly may experience more difficulty in taking care of their baby.

If you practice changing clothes and bathing using a baby doll in advance, you may feel less uneasy. Because many baby clothes have ribbons or buttons to fix them in place, you should sew hooks and loop fasteners on them to facilitate their change. Child-care becomes easier through actual experience.

When you attend child birth education classes held by a health center or hospital, ask the staff if any courses for practical child-care training are provided. Fathers' classes are also available.

Chapter 6.

Points to Be Considered in the Late Pregnancy Period (after the 28th week)

You will soon have your baby. You are no doubt full of hopes and concerns. It is important for you to relax your mind and body and spend your days as peacefully as possible.

1. Problems Frequently Encountered in the Late Pregnancy Period

Rapid growth of the baby may put extra burden on the mother.

1) Threatened Premature Labor

Threatened premature labor is a condition in which premature labor is about to take place or a condition that may result in premature labor. These conditions occur during the period from the 22nd to 37th gestation week.

(1) Warning symptoms

- a. Enlargement of the belly
- b. Abdominal pain
- c. Bleeding
- d. Increased vaginal discharge
- e. Others

Feelings of discomfort that are different from the usual ones, headache, back pain, low back pain, chest pain, cold sweats, increased spasm

[Countermeasures]

Prompt recognition of the above symptoms is of prime importance. As threatened premature labor is a condition in which premature labor is about to take place, prompt recognition of the condition and the introduction of appropriate treatment will enable pregnancy to be maintained until the 37th week or thereafter.

(2) Treatment

Assurance of the mother's safety is of prime importance. Hospitalization may be needed depending on the mother's condition. The physician may prescribe a drug that controls enlargement of the belly.

2) Preterm Delivery

If the baby is born during the period from the 22nd to 37th gestation week, the case is referred to as preterm delivery. Generally, preterm delivery is caused by

infection. If bacteria or viruses enter the uterus, they induce inflammation leading to uterine contraction and membrane rupture. Other causes of preterm delivery include maternal stress and uterine cervical incompetence. Caesarean section is usually indicated for preterm delivery, and the newborns are taken care of in the neonatal intensive care unit.

3) Early Rupture of Membrane

Rupture of the membrane is a term used during pregnancy to describe the rupture of part of the membrane of the ovum leading to the outflow of amniotic fluid. The mother recognizes neither pain nor bleeding but notices an outflow of lukewarm water. Rupture of the membrane usually takes place at the peak of contractions, but this event occurs before the initiation of contractions in the case of “early rupture of the membrane.” When the amniotic fluid flows out, bacteria may enter the uterus or the umbilical cord may come out along with the fluid. As these conditions may increase the risk for the mother, the mother should use the sanitary napkins or towels to control the outflow of amniotic fluid and hurry to the hospital. Do not take a bath. It may be difficult to differentiate rupture of the membrane from urine leakage. The odor and color of the fluids are the keys to differentiating rupture of the membrane from urine leakage. Yellow urine leakage has an odor of ammonia. Clear amniotic fluid has no odor or smells somewhat fishy. After the rupture of the membrane, in some cases labor starts, and the baby may be born prematurely.

4) Autonomic Hyperreflexia

The belly is noticeably enlarged as your baby moves more actively. Then, you notice an enhancement of such symptoms as headache, sweating, facial flush and goose bumps. Particular attention should be given to rapid elevation of blood pressure. Persistent high blood pressure may increase the risk of cerebral hemorrhage. If irritability is not improved through bed rest, call the hospital for advice.

5) Venous Thromboembolism

A blood clot formed in a leg vein (a mass formed when platelets or red blood cells coagulate in a vessel) travels through the bloodstream. The blood clot reaches a different vessel and blocks the blood flow there. If the blood clot is carried to the lungs and obstructs the pulmonary artery, it may induce serious pathological conditions including cardiorespiratory disorders.

[Countermeasures]

- a. Take care not to gain excessive weight.

- b. Massage your feet.
- c. Wear elastic stockings.
- d. Medications and physical therapy may be necessary for thromboembolism.

6) Spasm

As the belly is noticeably enlarged, you may experience enhanced spasm. You may feel a constriction in the chest and belly with difficulty in breathing. Because spasms may occur suddenly, sufficient care should be taken not to fall out of your wheelchair.

7) Difficulty in Breathing

As the baby grows up the diaphragm is pushed up. For this reason, you may experience difficulty in breathing. Generally, pregnant women who have a small lung capacity or cannot breathe deeply may suffer serious difficulty in breathing.

[Countermeasures]

- a. It is important to find a body posture which can facilitate breathing if only a little.
- b. Make a conscious effort to practice deep breathing on a routine basis.

2. Points to Be Considered in Daily Life during the Late Pregnancy Period

You may not be able to move easily because of your prominently protruding belly.

1) How to Perform Daily Activities

- * You may find it difficult to take prompt action and keep physical balance.
- * Take care not to slip or fall out of the bed or wheelchair when you are in a hurry. Constant attention is required whenever you move.
- * It is important for you to perform daily activities with time to spare.
- * Take care not to hit yourself on the belly.

(1) Transfer activity: Action to be taken when you move from or to the wheelchair*

You may find it difficult to move from the bed to the wheelchair, from the wheelchair to the toilet seat, and from the wheelchair to the car seat. You may be confident that you can complete such tasks with one easy movement, but a reckless attempt may hurt your wrists or arms.

Falling out of the wheelchair may result in a serious accident. Do not push yourself too hard. You can always ask someone for help.

(2) Toilet activities*

Defecation may require extra effort. In the restroom, you may find it difficult to insert suppositories or collect feces with your hands. Constipation may make the situation worse. When you are troubled by such a condition, you should consult with a nurse.

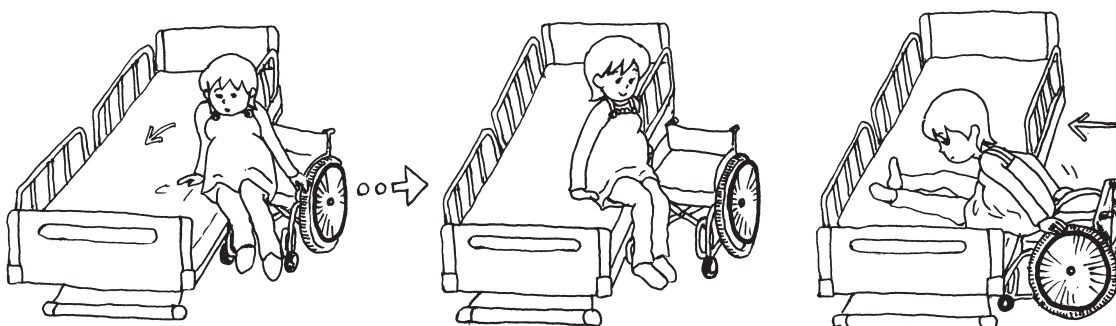


Fig. 3 Transfer activity

Footnotes

* Transfer activity

Transfer from the wheelchair to the bed, or from the wheelchair to the toilet seat.

Horizontal transfer: Take your feet out of the bed and move your hips from the bed to the desired place.

Rectangular transfer: Move directly to the wheelchair placed at a right angle to the bed without removing your feet.

* Toilet activities

Toilet activities include a series of actions for micturition or defecation such as moving from the wheelchair to the toilet seat, pulling down the underwear, inserting a suppository, collecting feces and wiping the bottom.

(3) Bathing

You may find it difficult to get into the bathtub. You can reduce your stress by asking your family members for help or taking a shower instead. Because you are very large with child, it may be difficult to keep your balance in the sitting position and you may fall down while washing yourself. Take care not to fall down while bathing.

(4) Changing clothes

Your feet may be hidden under your enlarged belly when changing clothes. In particular, it requires effort to put on socks and shoes. It also requires extra effort to roll over on the bed and change your pants. If you find it difficult to do these activities, you can ask your family members for support.

2) Tips for Doing Housework

You may be irritated if you cannot do housework as usual. Just think of your “coming delivery” and minimize the housework that you need to do.

- * Ask your family members for support.
- * Take rests during housework.
- * As long as your physician does not prescribe complete bed rest, you can move your body appropriately to prevent a decline in physical strength and excessive weight gain.

(1) Cooking

It may be hard to use the kitchen sink cabinet easily because of your protruded belly. Select simple dishes to facilitate cooking.

(2) Shopping

You should not put a basket on your knees. Use of a home-delivery service is recommended.

3) Going Out

You may need to go out for certain purposes such as prenatal checkups and shopping. As even a slight difference in level increases the risk of falling down, you should ask someone to attend you.

4) Going Out by Car

Driving is not recommended for pregnant women. You should select safer means of transportation during pregnancy. You can ask your family members to drive your car or take a train instead. But if there is no alternative but to drive by yourself, you should ask someone to get in the car with you.

- (1) Ask someone to drive your car whenever possible.
- (2) Ask someone to help with the loading and unloading of your wheelchair.
- (3) You may load and unload your wheelchair by yourself. In this case, you should pass it over your thighs.
- (4) Use of a board for transferring* is recommended to assure safety when you move from your wheelchair to the driver’s seat or the front passenger seat.



A board for transferring

Chapter 7.

Signs Indicating Initiation of Delivery

Various signs appear immediately before delivery.

1. Signs of delivery

- * Your enlarged belly comes down
- * You experience enlargement of the belly more frequently
- * Feeling of the enlargement of the belly increases
- * You may experience cramp at the base of the thigh
- * Vaginal discharge increases

2. Signs requiring immediate medical attention

- * Heavy bleeding or discharge of blood clots
- * Severe pain or fever
- * Rupture of the membrane
- * Labor is starting

3. What is labor pain

Labor pain appears when the uterus contracts to push your baby through the vagina. Women with reduced abdominal sensation occasionally feel no labor pain but complain of heavy feeling in the belly, pain around the hips and back, difficulty in breathing and nausea that they have never experienced before. Women with autonomic hyperreflexia may suddenly experience severe headache that occasionally suggests extreme elevation in blood pressure. In this case, they need immediate medical attention.



Chapter 8.

Delivery

Vaginal delivery occurs when a pregnant woman delivers her baby in the normal manner through the vagina. Caesarean section, which is introduced to assure safety of the mother and her baby, is also an important delivery method. Sufficient discussion with the physician is indispensable for successful delivery that satisfies both the mother and her family members.

1. Problems that May Be Encountered during Delivery

1) Weak Labor

Although labor has started, pain does not increase in some cases. Labor does not progress unless pain increases. If this condition continues, the pregnant woman may exhaust herself and the uterine contraction intensity may decline. Depending on the condition of the baby, Caesarean section may be selected.

2) Autonomic Hyperreflexia

It was reported that a pregnant woman suffered cerebral hemorrhage as a result of a rapid elevation in blood pressure. Since this incident, medical professionals have strictly controlled the blood pressure of pregnant women who have suffered injury of the spinal cord higher than the 6th thoracic cord. Pregnant women who have a past history of autonomic hyperreflexia are advised to consult their physicians or obstetric nurses in advance.

3) Pregnant Women with Spina Bifida

A pregnant woman with a protrusion on the hips or back cannot deliver her baby by conventional delivery or on the operation table because she may feel pressure on the protrusion and suffer headache or retching. Such pregnant women are advised to consult, in advance, with her physician, obstetric nurse or anesthesiologist about adjustment of the delivery/operation table.

2. After Delivery

Childbirth is an exhausting process for the pregnant woman. After labor, she needs to take sufficient rest for some time to prepare for the coming child-care. Compared with other pregnant women, however, those with spinal cord disorders generally need more time to recover their ordinary physical condition and their ability to do daily activities. They are advised not to push themselves too hard.

1) In the Case of Caesarean Section

After Caesarean section, the mother is instructed to take bed rest while receiving oxytocics and antibiotics. She is recommended to start physical exercise 24 hours after operation to prevent venous thromboembolism.

If the postoperative progress is satisfactory, she is allowed to leave the hospital about 10 to 14 days later.

2) Vaginal Delivery

After vaginal delivery, the mother is placed on complete bed rest in the delivery room for a few hours and allowed to go back to the patient room unless abnormal symptoms including bleeding and change of physical condition are detected.

3) Predictable Problems

(1) Delayed healing of an incisional wound in the perineum

Healing of an incisional wound may be delayed in women with spinal cord disorders whose perineal sensation is decreased.

[Countermeasures]

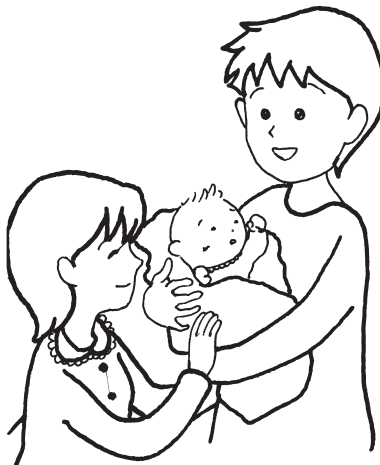
Keep the affected area clean.

- a. Constantly use a bidet toilet or gently wipe the affected area with clean cotton.
- b. Frequently change the napkins contaminated with lochia.
- c. If you notice abnormal discoloration or an offensive odor of lochia, consult your nurse.

(2) Pressure Ulcers

During labor, a pregnant woman pushes repeatedly on the delivery table. Remaining in a fixed posture for an extended period of time may result in the formation of pressure ulcers.

Consult your physician and obstetric nurse before starting labor.



Chapter 9. Taking Care of Your Baby

Because it is the first time for you to take care of your baby, things naturally do not go the way you want. Experienced mothers speak words of wisdom, “Enjoy what you can do instead of counting the number of things that you cannot do.”

1. Breastfeeding

It may be difficult to hold your fragile baby in your arms.

- a. You can feed your baby safely by lying down on the bed and holding him/her.



- b. You can feed your baby in your wheelchair while he/she is small. Set a cushion on your knees and place your baby on it for breastfeeding.



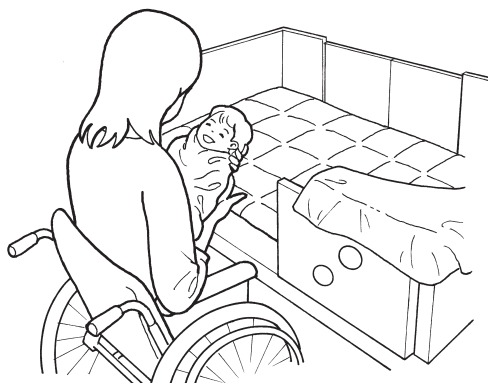
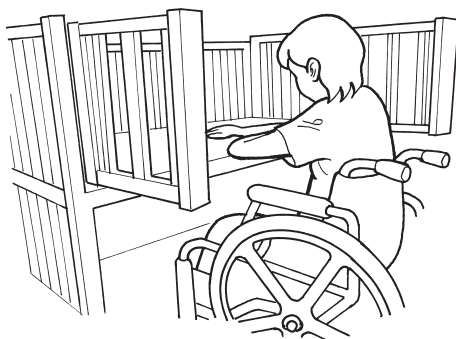
2. Changing Diapers/clothes

- a. You can change diapers/clothes in your wheelchair while he/she is small.



- b. You can safely change diapers/clothes by placing your baby in the crib when he/she grows up a little and moves more frequently. You can remodel the crib to facilitate such changing. For example, cut the lower frame of the crib to create a double swing door, which allows access to the crib from the front while sitting in your wheelchair to change diapers/clothes.

You should sew hook and loop fasteners in place of ribbons on baby clothes to facilitate their changing.



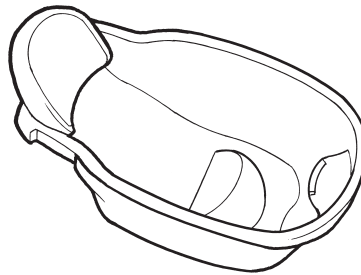
3. Bathing

Generally, mothers with spinal cord disorders ask their family members or friends to help them bathe their babies.

Some of these mothers cannot bathe their babies but they can enjoy bathing by gently wiping their babies' faces or talking to their babies.

a. Portable bathtub

You can use a portable bathtub with a stopper to support the baby's bottom and prevent him/her from slipping, as well as a pillow to support his/her head.



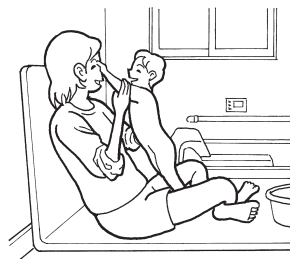
b. You can place the portable bathtub in the kitchen sink cabinet for bathing your baby. The mother is caressing her baby's cheek and her baby is happy.



c. You can place the portable bathtub on a table with wheels attached for bathing your baby.

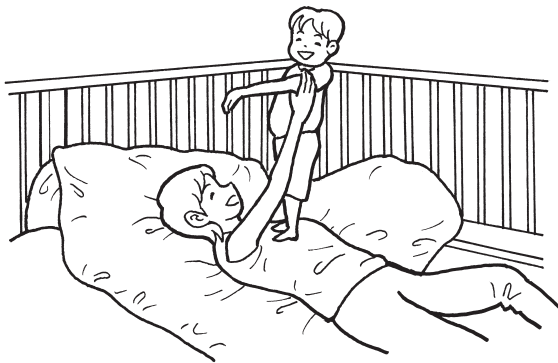
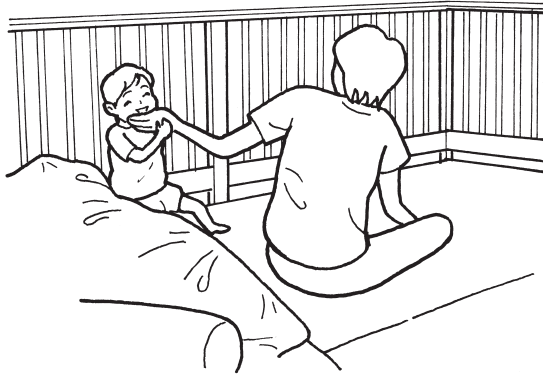


d. When your baby grows up, you can take a bath with your baby.



4. Playing

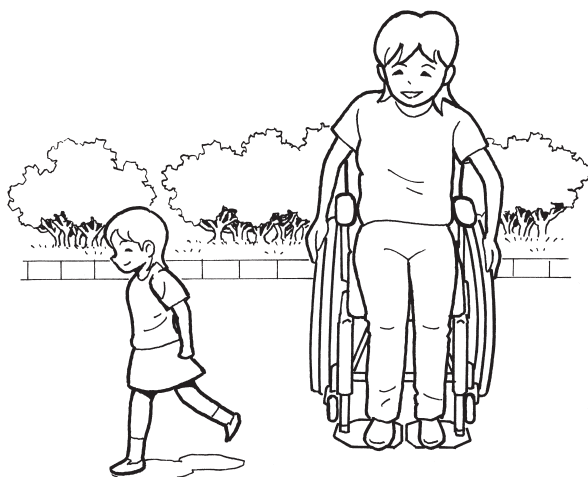
When your baby moves more actively, you may accidentally drop him/her or the baby may hit his/her head against something. Because there are many dangers in the living environment, you should prepare an area in the room where your baby can play safely.



5. Taking a Walk

You can safely take a walk with your baby by fixing him/her to your wheelchair with a baby sling. If your child can stand by himself/herself, you can stand him/her on the step of your wheelchair and fix him/her to your body with a sling.

When your child starts to walk by himself/herself, ask your family members or friends to take a walk with you and your child.



6. Others

1) When the mother or her baby became sick

It is very difficult to predict an acute fever developing in the baby. There are many occasions when you need to visit the emergency department of a hospital. Therefore, you should find persons who can attend you and your baby in the event of an emergency department visit.

2) When the baby suffers injuries

Your baby may become trapped under your wheelchair or may injure himself/herself by hitting his/her body against the casters, wheels or frames of your wheelchair.

Make sure that your baby is not around your wheelchair before you start to move it.



Chapter 10.

Voices of Women with Spinal Cord Disorders Who Have Experienced Delivery

Pregnancy and delivery for women with disabilities seem to be difficult experiences that can be shared only by those who have already gone through such.

The following are problems they faced and the anxiety they experienced.

1. During Pregnancy

1) Problems they faced in their daily lives

- a. I did not know how to defecate during pregnancy.
- b. I did not know why I felt ill.
- c. I did not know what I should be aware of in my daily life.

2) Hospital visits and consultations

- a. I could not find the parking area, restroom and scales for handicapped persons at the hospital.
- b. I could not sit in the special chair for a pelvic examination.
- c. As the frequency of hospital visits increased in the late gestation period, I found it difficult to always ask my family members to attend me. As a result, I missed some child birth education classes.
- d. Despite my efforts, my obstetrician hardly understood my explanation about spinal cord disorders.
* Obstetricians should know more about autonomic hyperreflexia.

3) Anxiety

- a. I wondered if I could have a baby despite having a spinal cord disorder.
- b. I was at a loss as to whom I had to consult with when I noticed my pregnancy.
- c. I wondered if my underlying spinal cord disorders and treatment (e.g., antibiotics, antispasmodics, and analgesics) might affect my baby.
- d. I wondered if the use of laxatives and the action of pressing the belly might result in miscarriage.
- e. I wondered if I could hold my baby in my arms and change the diapers.

4) At the Time of Delivery

Delivery method

- a. My obstetrician selected Caesarean section from the beginning.
- b. I could not fully accept the obstetrician's proposal to deliver my baby by Caesarean section under general anesthesia.



2. Voice of Experience

- a. It's great to have a baby !
- b. Preparation and responsibility to have a baby matured me as a person
- c. Let's be a mother with confidence and smile
- d. Don't worry too much. There are ways you could
- e. Let's have a place you can cry when you are in hard time
- f. Child-care is the best way of rehabilitation
- g. I am trying to create comfortable environment for my child and me by participating in children's and community activities.

3. Message from mother to children

- a. Thanks for coming into the world as my baby
- b. I hope my child have various experiences as a wheelchair user's child.
It will be helpful for future of my child.



Problems Frequently Encountered by Women with Spinal Cord Disorders and Necessary Instructions

	Physical symptoms frequently experienced by pregnant women in general	Physical symptoms frequently experienced by pregnant women with spinal cord disorders	Instructions
<p>Early gestation period</p> <p>0 to 15th week (1st to 4th month)</p>	<p>Miscarriage</p> <p>Hyperemesis</p> <p>Pollakiuria</p> <p>Constipation</p> <p>Nervousness</p>	<p>Miscarriage</p> <p>Anemia</p> <p>Urinary tract infection</p> <p>Autonomic hyperreflexia</p> <p>Vaginal infection</p> <p>Constipation</p> <p>Urine leakage</p>	<p>1) General instructions including the following points:</p> <p>Abnormal clinical signs</p> <p>How to visit the emergency department</p> <p>Expected date of delivery</p> <p>Necessity for physical examinations</p> <p>Mental health</p> <p>Sexual life</p> <p>Nonsmoking education</p> <p>How to relieve morning sickness</p> <p>Sanitary management</p> <p>2) Physical symptoms frequently experienced by pregnant women</p> <p>3) Reduced activity of daily living</p> <p>4) Use of medications</p> <p>5) Others</p>
<p>Mid-pregnancy Period</p> <p>16th to 27th week (5th to 7th month)</p>	<p>Weight gain</p> <p>Stress on the kidneys resulting from increased renal blood flow</p> <p>Pregnancy-induced hypertension</p> <p>Increased vaginal discharge</p> <p>Breathing hard</p> <p>Varicose veins</p>	<p>Anemia</p> <p>Pregnancy-induced hypertension</p> <p>Threatened premature delivery</p> <p>Anemia</p> <p>Urinary tract infection</p> <p>Edema of the lower extremities</p> <p>Pressure ulcers</p> <p>Vaginal infection</p> <p>Enhanced spasms</p> <p>Autonomic hyperreflexia</p> <p>Feeling of difficulty in breathing</p> <p>Urine leakage</p>	<p>1) General instructions including the following points:</p> <p>Taking care of the nipples</p> <p>Precautions to be considered in daily life</p> <p>Dental hygiene</p> <p>2) Physical symptoms frequently experienced by pregnant women</p> <p>3) Weight control</p> <p>4) Preparation for having a baby</p> <p>Preparation of baby goods</p> <p>Environmental adjustment</p>
<p>Late gestation period</p> <p>28th week and later (8th month and later)</p>	<p>Preterm delivery</p> <p>Pregnancy-induced hypertension</p> <p>Anemia</p> <p>Massive bleeding due to placenta previa/uterus rupture</p> <p>Pollakiuria</p> <p>Stomach pressure sensation</p> <p>Breathing with the chest</p> <p>Frequent urge to urinate</p> <p>Increased vaginal discharge</p> <p>Nervousness</p>	<p>Threatened premature delivery</p> <p>Preterm delivery</p> <p>Early rupture of the membrane</p> <p>Autonomic hyperreflexia</p> <p>Anemia</p> <p>Pregnancy-induced hypertension</p> <p>Urinary tract infection</p> <p>Enhanced edema</p> <p>Pressure ulcers</p> <p>Vaginal infection</p> <p>Enhanced spasms</p> <p>Sensation of difficulty in breathing</p> <p>Urine leakage</p>	<p>1) General instructions including the following points:</p> <p>Abnormal clinical signs</p> <p>Precautions to be considered in daily life</p> <p>Prevention of pregnancy-induced hypertension</p> <p>Breast feeding</p> <p>2) Physical symptoms frequently experienced by pregnant women</p> <p>3) Preparation for hospitalization</p>

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