INTRODUCTION

Women with spinal cord injury or dysfunction (SCI/D) face a number of unique health care needs. Because women represent only about 20 percent of all individuals with SCI/D, there is limited information on their unique health and wellness issues. Much of the available information is also outdated, especially the information related to pregnancy, labor and delivery.

First, the facts are simple. No matter what the level of injury or dysfunction, women with SCI/D...

- can, and do, have children.
- share the same parental responsibilities of all women.
- must decide whether they are physically, emotionally, and financially prepared for the responsibilities of a baby.
- must know how their bodies will change and how to best avoid complications during pregnancy.
- need birth control if they do not want to become pregnant.

Second, it is essential for women with SCI/D as well as doctors and other healthcare providers to know all of the facts related to pregnancy, labor and delivery.

UNDERSTANDING PREGNANCY

Education is the key for women with SCI/D to understand pregnancy. With the proper education, you can make an informed choice on whether or not to become pregnant. If you become pregnant, you will be better prepared to manage your pregnancy.

You can begin your education by talking with a rehabilitation physician (physiatrist) who is very familiar with the reproductive health concerns of women with SCI/D. A physiatrist can explain the many unique medical, psychological and social issues that you may face. You can learn about potential complications during pregnancy and delivery and ways that you might prevent and manage them.

Your physiatrist can help you find an obstetrician to help you manage your reproductive health. You want to find an obstetrician who understands, or is willing to learn, your unique needs. This is important because many doctors and other health care providers are not familiar with the issues of women with SCI/D. Those who do not know about women’s issues might encourage you to not become pregnant. Some may even recommend an unnecessary, undesired abortion if you do become pregnant.

PREPARING FOR PREGNANCY

Once you have an obstetrician, there are a number of concerns that need to be addressed if you are thinking about having a baby. If you become pregnant before talking to your obstetrician, you should contact your obstetrician immediately.

Medications
Many prescribed and over-the-counter medications normally used by women with SCI/D can cause, or add to, problems during pregnancy. Some medications can also have an adverse affect on fetal growth. Therefore, it is essential that all medications (including vitamin supplements) be evaluated by your obstetrician before pregnancy and continually re-evaluated each trimester. Some conditions that you might manage with medications include bowel management, pain, sexual dysfunction, muscle spasms, and urinary tract infection (UTI).

Urologic Check-up
You should first have a complete urologic exam if you are planning to have a baby. X-rays should not be taken during pregnancy unless absolutely necessary. They can harm the fetus. You and your obstetrician can discuss what type of urologic follow-up care that you need during your pregnancy.
Physical Changes
Some women with SCI/D have skeletal abnormalities such as curvature of the spine, pelvic fracture, or hip dislocation. These conditions can limit the space in the abdomen necessary to carry a full-term fetus. These abnormalities can also make vaginal delivery difficult.

Team Approach
If your obstetrician has limited experience managing pregnancies of women with SCI/D, it is recommended that you take a “team” approach to your pregnancy. You and your obstetrician can consult with an experienced physiatrist, nurse, urologist, anesthesiologist, neurologist, respiratory therapist, physical therapist, and occupational therapist on specific concerns about pregnancy, labor and delivery.

PREGNANCY

“High risk” describes an increased chance for complications during pregnancy. Women with SCI/D may be considered to have “high risk” pregnancies. However, it does not mean that pregnancy should be avoided. It simply means that you need to take precautions to prevent and treat complications.

It is impossible to predict if, or when, complications will occur. Some complications are easier to manage than others. Some may occur early on in pregnancy and go away in time. Others may continue to be a problem throughout pregnancy and delivery.

Each trimester brings the possibility of new challenges. Therefore, it is very important for you and your obstetrician to be aware of the potential problems that may occur. Both of you should work together to develop a plan to prevent medical complications when possible and be aware of ways to manage problems if they occur.

1ST Trimester
Mood swings, dizziness, headaches, fatigue, heartburn, indigestion and nausea are some of the natural changes that most women experience during their first trimester. These natural changes usually go away in time. As a woman with SCI/D, however, you should know that some of those natural changes can also be signs of complications. For example, a headache can be a symptom of autonomic dysreflexia (AD). A headache with nausea might be a symptom of a UTI. Therefore, you should keep your obstetrician well informed on symptoms that might suggest other problems.

Bowel Management can be a problem as early as the first trimester. Two of the most common changes that occur during pregnancy include constipation or diarrhea. Depending on the problem, your obstetrician may suggest that you increase or decrease your water or fiber intake. It may also be necessary to empty the bowels more frequently or take a stool softener or laxative - but only if prescribed by your obstetrician. (see InfoSheet #9 for more on bowel management)

2ND Trimester
The potential for complications increases during the second trimester. As you and your obstetrician work to manage complications, it is important to remember that methods of managing a complication can change from trimester to trimester. In other words, your method for managing your bowel program in the first trimester may not be as effective in the second or third trimester. Therefore, you may need to find different solutions for the same problem.

Weight gain is a major concern. It can interfere with your ability to perform everyday activities. For example, you may have difficulty transferring or pushing your wheelchair. You may quickly tire from doing activities that you did with ease before pregnancy.

The solution to problems related to weight gain will vary. You might reduce the number of times that you transfer if that becomes a problem. You can rent or purchase a power wheelchair if you have trouble pushing your manual wheelchair. It may also be necessary to get assistance from others or find new ways to accomplish everyday tasks.

Bladder management is a common complication. As the fetus grows, there will likely be increased weight on the bladder. The pressure decreases bladder capacity, which can lead to an increase in bladder spasms.

Women using intermittent catheterization will likely need to catheterize more often, or it may be better for some women to switch to an indwelling catheter during pregnancy. However, women with indwelling catheters may experience leaking.
Urinary tract infection may be a problem. As a woman with SCI/D, you have a greater chance of getting a UTI during pregnancy. In fact, a UTI might actually trigger premature labor if not properly managed.

Prevention is the best way to manage a UTI. Obviously, you need to drink plenty of water and avoid drinking beverages with sugar, caffeine and especially alcohol. You can also catheterize more often. If you have a history of infection or get a UTI, your obstetrician may prescribe an antibiotic to prevent or manage an infection.

If you experience symptoms of infection (fever, chills, nausea, headache, changes in spasticity, unusual pain/burning, or AD), your obstetrician should get a urine sample before treatment. This helps to identify the most safe and effective antibiotic for treating the infection. Plus, it can confirm that you have no other health problem. (** see InfoSheet #11 for more on bladder management and UTI)

Pressure sores are always a concern for women with SCI/D, but women who are pregnant are at an even greater risk for developing pressure sores. This increase in risk is primarily due to weight gain and/or posture changes.

It is essential to prevent pressure sores when possible. You should take special care to prevent abrasions when doing transfers. It also helps if you increase the number of pressure reliefs. You need to check your skin more often and get help with pressure reliefs and skin checks if needed. You should watch for posture changes while sitting in your wheelchair and talk with a physical therapist to change your seating position if needed. If you notice signs of a pressure sore, stay off the area, and call your doctor right away for advice on treatment. Your obstetrician can also include skin inspections as part of your prenatal examinations starting in the second trimester. (**see InfoSheet #13 for more on pressure sores)

Muscle Spasms may or may not be a concern during pregnancy. If you normally experience muscle spasms, there is a chance of an increase or decrease in your muscle spasms during pregnancy. If you do not normally have muscle spasms, there is a chance that spasms will develop.

Typically, muscle spasms are only treated if they interfere with your everyday activities or put you at greater risk of a pressure sore. As a precaution, however, you should talk to your obstetrician if you notice any changes in your muscle spasms. Chances are it is simply a result of your pregnancy, but a sudden change in muscle spasms can sometimes be a sign that there is some other health problem. (** see InfoSheets #16 for more on muscle spasms)

3rd Trimester

Respiratory complications can be a problem for some women. If your injury or dysfunction is in the cervical and thoracic areas of the spine, you likely have a loss of respiratory muscle control. A higher level of injury results in a greater loss of muscle control, and any loss of respiratory muscle control weakens the pulmonary system, decreases lung capacity, and increases respiratory congestion. As a result, it is more difficult to take deep breaths and cough, which increases the risk for respiratory complications such as pneumonia. In addition, growth of the fetus puts pressure on the diaphragm, which can further decrease lung capacity and expansion in women with cervical and thoracic injuries. Therefore, the risk for respiratory complications increases even more.

The best way to prevent serious respiratory problems is through proper positioning and added rest. If you normally wear an abdominal binder to improve your diaphragm function, you may need to loosen the binder or not wear it during pregnancy. Your obstetrician might suggest breathing exercises. If you have a high level of injury or dysfunction, your obstetrician may need to monitor your ventilatory function and provide ventilatory assistance if needed. (** see InfoSheets #19 for more on breathing exercises and other respiratory issues)

Blood flow is another problem that develops in the last months of pregnancy. Pressure from the growing fetus can hinder blood flow in the lower extremities, so you may have swelling in your legs and feet.

To help improve blood flow and reduce swelling, you can wear circulation-promoting hose, get extra rest, and do passive range of motion exercises. If you have a history blood clots, your obstetrician can prescribe a medication to help prevent clots from forming.
LABOR & DELIVERY

Again, you and your obstetrician should plan well before your expected due date on how to prevent or manage possible problems during labor and delivery. First, bowel and bladder management, UTI, muscle spasms and blood flow can continue to be problems during labor and delivery. You need to also pay careful attention to your skin care and watch for problems with high or low blood pressure. Second, you should go to labor and delivery classes if possible. These classes can be very helpful in informing you on issues that all women face. Third, the labor, delivery and patient rooms should be made fully accessible if needed.

Labor
Some women with SCI/D notice normal signs of labor, but others do not. You may not feel labor pain if your injury or dysfunction is level T-10 and above. On the other hand, you might experience uterine contractions if your injury or dysfunction is lower than T-10, but the feeling is usually different from able-bodied women. Although some women may feel the initial contractions, that sensation may pass as labor progresses. Therefore, you and your obstetrician might discuss if, or when, to induce labor.

As a precaution, you and your obstetrician should watch for signs of labor starting at around 28 weeks. Your obstetrician might perform a weekly cervical examination. Women with paraplegia should learn how to do uterine palpation to help detect labor. Some women with tetraplegia might request a home uterine contraction monitor. Plus, all women with SCI/D need to watch for common signs of labor that include:

♦ feelings of fear and anxiety;
♦ changes in spasticity or breathing;
♦ backache;
♦ abdominal tightening;
♦ pelvic pressure;
♦ unusual feelings of pain; and
♦ autonomic dysreflexia.

Autonomic dysreflexia is common during labor and can be life-threatening if not managed properly. AD is most common for women with injury or dysfunction at levels T-6 and above. However, there is some evidence that AD can occur during labor in women with SCI/D much lower than T-6. Although some women might not need anesthesia due to a lack of sensation, a continuous epidural anesthesia is considered to be the most effective method of preventing AD during labor.

Delivery
Typically, your delivery should be beautiful and natural. Most women can, and should, deliver vaginally whenever possible. Some may deliver with ease, and some may need the assistance of a vacuum device or forceps. Although you and your obstetrician might discuss the possibility of Caesarean section (C-section), neither of you should assume that a C-section is preferred simply because you have SCI/D.

AFTER DELIVERY

There are a few concerns for women with SCI/D after delivery. First, if you had an episiotomy, do not use a heat lamp on an area with no sensation to aid in healing. You may get burned. Second, you may feel faint or dizzy when you try to sit up after delivery. To ease this problem, you can sit up slowly, wear elastic hose, or use an abdominal binder. Finally, you have to decide whether or not breast feeding is right for you. Although breast feeding is possible for most women, you may notice an increase in your spasticity as you breast feed. Also, breast feeding normally stimulates the production of breast milk, so women with limited sensation in their nipples may notice a reduction in milk.

CONCLUSION

As a woman with spinal cord injury or dysfunction, do not rely on assumptions when it comes to pregnancy, labor and delivery. Do not let friends, family members and even doctors convince you to not have a baby simply because you have SCI/D. Instead, you should rely on the facts about pregnancy from health care professionals that clearly understand the reproductive needs of women with SCI/D. Although there are risks for complications related to pregnancy, you can reduce and manage those risks with proper prenatal care and adequate planning.

Once you know the facts, it is up to you to decide if, or when, you want to have a baby. If you choose to have a baby, you can enjoy everything that being a Mother has to offer.
WOMEN W/DISABILITY RESOURCES

Center for Research on Women with Disabilities
3440 Richmond Avenue, Suite B
Houston, Texas 77046
Phone: 713-960-0505 Toll Free: 800-44-CROWD
Email: crowd@bcm.tmc.edu
Web: www bcm.tmc.edu/crowd/
CROWD is a research center that focuses on issues related to health, aging, civil rights, abuse, and independent living. CROWD’s purpose is to promote, develop, and disseminate information to expand the life choices of women with disabilities so that they may fully participate in community life.

Department of Rehabilitation Medicine
University of Washington
Box 356490
Seattle, WA 98195-6490
Phone: 206-543-3600
Email: rehab@u.washington.edu
Web: http://depts.washington.edu/rehab/sci/forum-reports.shtml
The SCI Forum is an evening presentation and discussion series on topics of interest to persons with spinal cord injury and their friends, family members, and caregivers. They offer varying topics such as relationships, sexuality, dating, parenting, childbirth, fertility and more. They also post summary reports on past SCI Forums.

Health Promotion for Women w/Disabilities Project
Villanova University - College of Nursing
800 Lancaster Avenue
Villanova, PA 19085
Phone: 610-519-4922
Email: Vanessa.Zimmerman@Villanova.edu
Web: www.nursing.villanova.edu/WomenWithDisabilities/
The Project provides information for women with disabilities so they can be informed consumers of health care, can ask relevant questions of their health care providers, and can take measures to achieve a healthier life style and a better quality of life.

Parents with Disabilities Online!
Web: www.disabledparents.net/index.html
This is a great site if you are a parent with a disability, a person with a disability who is planning to become a parent, or a nondisabled partner of a disabled parent. It has accessible/independent parenting information on pregnancy, childbirth, and reproductive health issues; general issues of child care and child rearing.

Rehabilitation Institute of Chicago
345 East Superior Street
Chicago, IL 60611
Phone: 312-238-1051 Toll Free: 800-354-REHAB
Web: www.rehabchicago.org/community/hrcwd.php
RIC’s Health Resource Center for Women with Disabilities provides accessible, comprehensive health services for women with disabilities. They develop and implement advocacy programs, clinical services, research, and resource networks that empower women with disabilities, and they educate professionals on health and cultural issues.

** Spinal Cord Injury Information Network
UAB - Dept of Physical Medicine & Rehabilitation
Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
Phone: 205-934-3283
Email: RTC@uab.edu
Web: www.spinalcord.uab.edu
This site is maintained by the Rehabilitation Research and Training Center (RRTC) on Secondary Conditions of Spinal Cord Injury, which offers a poster on managing Autonomic Dysreflexia, a 5 part multimedia series, 2 videos, 3 newsletters and 20 InfoSheets**. Some featured topics of information include women’s sexuality and reproductive health. The site also offers links to other web sites with information on disability and spinal cord injury.

Through the Looking Glass
2198 Sixth Street, Suite 100
Berkeley, CA 94710-2204
Phone: 800-644-2666 or 510-848-1112
Email: TLG@lookingglass.org
Web: www.lookingglass.org
An excellent site for all women with disabilities. It provides a newsletter, books and other materials on available clinical and supportive services, training and research to families with either a parent or child with a disability. They also offer a Parent-to-Parent network where parents and those who are considering becoming parents can share their experiences.
Women’s Health Resources

Canadian Women’s Health Network
419 Graham Avenue - Suite 203
Winnipeg, Manitoba Canada R3C 0M3
Phone: 204-942-5500 Toll free: 888-818-9172
Email: cwhn@cwhn.ca
Web: www.cwhn.ca
CWHN is a Network of individuals, groups, organizations and institutions concerned with issues of women’s health. The CWHN recognizes the importance of information sharing, education and advocacy for women’s health and equality. It strives to build and strengthen the women’s health movement in Canada and throughout the world.

Health Resources and Services Administration
US Department of Health and Human Services
Parklawn Building
5600 Fishers Lane
Rockville, Maryland 20857
Phone: 1-888-Ask HRSA (275-4772)
Web: www.ask.hrsa.gov
HRSA offers publications, resources, and referrals on health care services for low-income, uninsured individuals and those with special health care needs. Some topics of information include women’s health and maternal and child health (also available en Español).

National Women’s Health Information Center
8550 Arlington Blvd. - Suite 300
Fairfax, VA 22031
Phone: 800-994-WOMAN
Web site: www.4woman.gov
This web site and toll-free call center was created by the US Department of Health and Human Services to provide a FREE, reliable health information source for women everywhere. Browse the database for great resources or take a look through our Special Sections on topic areas like heart disease, disabilities and pregnancy.

Internet Resources

BabySite.org
Personal information about pregnancy and birth, as well as contributions from people around the world.

Childbirth.org
Professionals offering educational information to consumers on how to provide the best possible care are essential to a healthy pregnancy. Enjoy the many links of educational, informational, and personal nature.

FamilyCareIntl.org
Family Care International is dedicated to improving women’s sexual and reproductive health and rights in developing countries, with a special emphasis on making pregnancy and childbirth safer.

iVillage.com
A women’s network sharing solutions and advice on issues such as beauty, books, diet and fitness, entertainment, health, home and garden, money, parenting, pregnancy/babies, relationships and work.

ParentsPlace.com
A great part of iVillage offering information for women trying to conceive. Some topics include fertility, adoption, pregnancy, baby, breastfeeding, twins and multiples.

Pregnancy.org
A site built by parents for parents banded together to educate, empower, and connect parents and people trying to become parents.

PregnancyGuideOnline.com
For each of the 40 weeks of pregnancy, you’ll find information about baby’s development, the types of changes that occur within mom’s pregnant body, tidbits for dads, specific info for pregnant moms of multiples and suggested readings.

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(205) 934-3283 or (205) 934-4642 (TTD only)
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Developed by: Phil Klebine, MA; Linda Lindsey, MEd
Consultants: Amie B Jackson, MD; Robert Poczatek, MD
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