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Pregnancy After SCI: A Story of Two Women

by Shirley Estill

Having children is a dream that starts at childhood for most women. Maternal instincts are usually strong, and the desire to have children often becomes a top priority in life.

As a woman with spinal cord injury (SCI), you are likely to want to have children. Only now you may think that you cannot become pregnant or that your body cannot handle a pregnancy. You may feel that you can no longer perform the duties of a parent because of your physical limitations after injury.

However, the truth is completely opposite. Women with SCI have children. They are fully able to become pregnant and manage the physical demands of pregnancy and parenting.

Angeline

When Angeline decided to have a baby in 1968, no one knew what to expect. At the time there was very little information available on SCI and even less on pregnancy after SCI. But that did not stop Angeline. She had always figured out ways to accomplish her goals. “I was so naive back then,” Angeline recalls. “I didn’t worry about things that I couldn’t control. I lived my life from day to day and did everything I wanted. My family encouraged me. We lived by the philosophy that life goes on, and we’ll do what needs to be done.”

After Angeline graduated from college, she decided to marry Don, who is now her husband of 35 years. “We didn’t talk about my disability or about having children. We just knew that we were in love and wanted to get married.” When she became pregnant, Angeline was well adjusted to life with a disability. She had the self-confidence and self-assurance that she would need to be a parent. “I felt I didn’t need to worry about having a baby in advance when I didn’t know what would happen. I’d been independent enough to know I could handle the challenges ahead,” she explains.

And the challenges did come. One problem that Angeline encountered during pregnancy was a decrease in mobility due to weight gain. This made it harder for her to do transfers. There were problems managing daily living activities. For example, it became more difficult for her to get dressed and complete her bowel program. She solved the problem by allowing extra time...
to do everything slowly and cautiously. She also had trouble distinguishing false labor from true labor. Close monitoring was necessary during the last few weeks of the pregnancy.

With challenges of pregnancy met, labor and delivery went smoothly. Angeline and Don welcomed their first daughter, Meri Kelly. Three years later Angeline gave birth to their second daughter, Alexandra, who also arrived without any problems.

Angeline and Don figured out ways to simplify parenting tasks. Don built a table that Angeline could roll her wheelchair under to allow her to change diapers. He further modified the table by cutting a hole in the top for an infant’s bathtub. When shopping and doing other activities, Angeline devised a strapping system to keep the children secure in her lap. A strap was attached to her wheelchair and around the children. This kept them from sliding out of her lap.

Today, Angeline has three grandchildren and continues to lead an independent and productive life. Her advice to women with spinal cord injury who want to have children, “Don’t let your concerns outweigh your opportunity to try something you really want to do. Everything may not turn out the way you expect, but at least you’ve tried and you can look for different ways to accomplish your goals.”

**Melissa**

Pregnancy was also a time for adjustments for Melissa, who has a T5 level of injury from a car accident at age 17. Thinking back on her pregnancy, Melissa remembers, “The extra weight gain made transfers more difficult, and I was afraid of falling.”

Her husband, Bo, built a ramp that led to a level platform beside the bed. This raised Melissa’s wheelchair to the same level as the bed, making the transfer less difficult. Bo adjusted the couch with blocks to raise it up and help make her transfers to the couch easier.

Melissa also had to change her bladder management program during the pregnancy. With her intermittent catheterization program, she was experiencing frequent bouts of incontinence. Changing to an indwelling catheter for the remainder of the pregnancy resolved this problem.

However, things got complicated during labor. After experiencing false labor, Melissa’s true labor started late at night seven weeks before her due date. She felt her stomach tightening and called 911. Paramedics soon arrived to find Melissa with a severe headache, high blood pressure, and blurred vision. The paramedics were not familiar with people with spinal cord injury. They did not know Melissa was experiencing Autonomic Dysreflexia (AD) and needed urgent medical attention. AD is a life threatening condition that can occur in persons with spinal cord injury at or above the T6 level. Melissa remembers, “I was really scared! When they took my blood pressure I thought it was too high, but they said that wasn’t unusual.”

Fortunately, Melissa arrived at the hospital just in time. She got there at 12:52 in the morning and her daughter, Carly, arrived at 1:05. Melissa had a normal vaginal delivery and the effects of AD soon diminished. Being premature, Carly had to stay at the hospital for twelve days with a collapsed lung. Now two years old, Carly is a beautiful, outgoing toddler exhibiting no evidence of her dramatic entry into the world.

Despite the dangerous labor and the lifestyle inconveniences of pregnancy, Melissa feels fortunate. She explains, “I call Carly my little angel. Several years ago an abscess formed in my abdomen that scarred my ovaries and fallopian tubes. I was told that I would have a very slim chance of getting pregnant. Then I got pregnant and I couldn’t believe it!”

**Conclusion**

Having a baby can be a dream come true, but it requires sacrifice and commitment. Women with spinal cord injury may find it necessary to change personal care routines during pregnancy, such as bowel and bladder programs. You may need to modify your home to better manage parenting.

For a free InfoSheet on Pregnancy and Women with SCI, go to [www.spinalcord.uab.edu/show.asp?durki=22442](http://www.spinalcord.uab.edu/show.asp?durki=22442) or contact the Office of Research Services at the address on page 8.
**myth or fact? parenting after SCI**

**Myth:** Individuals with SCI cannot have children after injury.

**Fact:** There are some people, maybe family, friends, and even doctors, who may suggest that you cannot have a baby. They may think it is either impossible or too dangerous for women. They may think it is also impossible for men. Those who know the facts about SCI disagree.

**Women:** It is common for your menstrual cycle to stop for a short time after you are first injured. But your ability to become pregnant returns when menstruation resumes. As a woman with SCI, your pregnancies are considered "high risk" due to the unique complications that can occur. Your lung capacity may decrease as your fetus grows and your uterus enlarges. Your risk of pneumonia increases, especially if you have tetraplegia. There is more of a chance for a pressure sore as your weight increases. You have a greater chance of developing blood clots in the veins in your legs. You may need to adjust your bowel and bladder management programs because of constipation, incontinence, or bladder spasticity. You may experience autonomic dysreflexia (AD), which is a life threatening condition. Transfers, movement in bed, personal care, and other daily activities may become more difficult because of limited mobility in the later stages of pregnancy.

Labor and delivery is a natural process and not usually effected by SCI. You may, however, experience some symptoms that are unique to women with SCI. These symptoms may include increased spasticity, AD, increased bladder spasms, and a problem with your blood pressure during delivery. There is some evidence that suggests that you may have a greater risk for premature (prior to 36 weeks gestation) labor and delivery.¹

You want to be prepared for all possible complications and physical changes during pregnancy. You can start by learning about pregnancy after SCI. Then, take a team approach to your pregnancy that includes you, your obstetrician and a physiatrist (a doctor specializing in rehabilitation medicine).

**Men:** Sexual functioning and fertility can be obstacles for men with SCI who want to become fathers (see page 4 for details).

**Myth:** Individuals with SCI should be discouraged from becoming parents, especially if they need help with their own care.

**Fact:** People with children before their injury do not suddenly lose their ability to parent after SCI. They continue to provide love and care for their children, no matter what their level of injury. This fact also applies to those who want to become parents.

If you are living with SCI, you are likely very good at finding ways to get things done. Parenting is no different. Parents with SCI can, and do, work with their partners to find ways to get things done. There are many different ways to help you care for your child. You can use adaptive devices such as velcro diaper covers and a chest harnesses to carry your baby. Occupational therapists who work with persons with SCI can be a good source for learning about such assistive devices. They may also have ideas on ways that you can adapt things in your home to better maximize your ability to care for your child. Parents commonly share parenting duties. Parents with SCI can also share duties with their partners. For example, one parent might be responsible for bathing their child. The other can be responsible for reading. This type of "task assignment" allows each parent to use their own abilities.

Also, some people may wrongly assume that parents should never have to ask for help in caring for their children. But asking for help and receiving it from others is part of being a parent. Parents usually get help in many ways and from many people, such as family members, day care providers, teachers, and many others. For example, you may ask a day care worker to help put your child in a car seat. It is very rare for parents to care for their child without any help from others. This fact is no different for parents with SCI. At times you may need to ask for help to simply get things done.


This article was written by the editor. Other resources are available on page 8.
Many men with spinal cord injury (SCI) and their partners want to have children after injury. In fact, there are some couples that have little or no difficulty achieving pregnancy. However, most men with SCI have problems with either sexual functioning, fertility, or both. These problems must be solved if couples are ever to become parents.

The Miami Project to Cure Paralysis has published "A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction." It is a 44-page booklet and serves as an excellent source of information for both men with SCI/D and their partners. It discusses potential obstacles in achieving pregnancy and ways that couples can overcome those obstacles and become parents after injury. This article is a brief overview of that booklet.

**Erectile Function**

An erection occurs when blood flow increases to the penis causing it to become stiff, or erect. Normally, two types of sexual stimulation cause erections. *Psychogenic erections* occur when the brain reacts to sights, smells, and sounds of sexual activity. The brain sends signals through the spinal cord to produce an erection. *Reflexogenic erections* occur in response to direct stimulation of the penis and without input from the brain. Men usually get an erection through a combination of both psychogenic and reflexogenic stimulation.

The purpose of an erection is to engage in sexual activity. The ability for men with SCI to have and maintain an erection is different for each person. It can depend on the level of injury and whether the injury is complete or incomplete. Many men with SCI can no longer have psychogenic erections as a result of the injury to their spinal cord. However, some men do retain their ability to have reflexogenic erections after injury and have no problem engaging in sexual activity. Others have reflexogenic erections that only last a short time, or their erection is not stiff enough to allow for sexual intercourse. Finally, some men lose their ability to have both psychogenic and reflexogenic erections after injury.

It is important for men with SCI to solve their problems with erectile function even if they do not want to have children.

Viagra® (sildenafil citrate) is a pill that is taken to help men have an erection. It is typically taken between 20 and 60 minutes before sex. Viagra helps to open blood vessels allowing increased blood flow into the penis. Studies have shown that up to 75% of men with SCI report an improvement in the ability to have an erection using Viagra.

**Injectable Medications**, such as Caverject®, can be effective in allowing men to quickly have an erection. The medication is injected through a syringe and needle into the penis. The erection occurs when blood vessels open to allow the penis to fill with blood.

A **Vacuum Device** is a cylinder with an attached vacuum pump. The cylinder is placed over the penis and air is drawn out of the cylinder by the pump. This process pulls blood into the penis to produce an erection. A tension ring is placed at the base of the penis to maintain the erection.

**Penile Implants** are also available. These devices are surgically inserted in the penis. Implants usually consist of an extending chamber within the penis. A water reservoir may then be used to pump water into the chamber to produce an erection.

**Ejaculatory Function**

Ejaculation is the process of delivering semen from the urethra through the penis. Semen contains sperm, which are needed to achieve pregnancy. The brain normally sends signals through the spinal cord and coordinates the ejaculatory process with the erection.

Although most men with SCI can have erections either naturally or through other options, about 90% of men with SCI are not able to ejaculate on their own. This is a problem for those men who want to be fathers. If they cannot ejaculate during intercourse, they must rely on alternative methods to induce ejaculation.

**Masturbation** is the stimulation of the penis with the hand or other method. Masturbation may result in ejaculation for men with SCI because the stimulus can be more intense than sexual intercourse. **Penile Vibratory Stimulation (PVS)** is a vibrating device used for masturbation. Studies show PVS is relatively effective in inducing ejaculation for 60 to 80% of men with T10 levels of injury and higher.

If masturbation is not successful in producing ejaculation, men with SCI who want to become fathers may find success...
with Rectal Probe Ejaculation (RPE). RPE is done by a doctor and can induce ejaculation for many men with SCI. This method requires the insertion of an electrical probe into the rectum to stimulate ejaculation. If RPE is not successful, doctors can surgically retrieve sperm directly from the man's reproductive tract.

**Potential Problems**

Men with SCI should always consult a doctor familiar with SCI/D and its effects on fertility before trying any treatment option. Medications like Viagra and Caverject can have serious and sometimes life-threatening effects. Autonomic Dysreflexia (AD) is a life threatening condition and can be a major concern for men with SCI trying to induce ejaculation.

Some men may also face other medical problems unique to men with SCI. Retrograde ejaculation is one such problem. This occurs during ejaculation when the semen enters the bladder instead of exiting through the penis. Semen quality is also a major concern for men with SCI. Semen quality describes the sperm within the semen. Normally, men produce a large number of sperm during ejaculation. For most men, about 70% of the sperm they produce are considered motile. Motile sperm are alive and very active. The greater the number of motile sperm, the greater the chances are for achieving pregnancy. Graph 1 shows that semen of men with SCI usually contain a normal number of sperm, but the sperm have low motility. This means that most of the sperm are not active. Graph 2 shows that only about 20% of sperm from men with SCI are considered motile compared to about 70% of sperm from able-bodied men.

**Getting Pregnant**

Pregnancy results when the sperm from a man fertilizes the egg from a woman. This fertilization process typically begins during sexual intercourse as the sperm is ejaculated into the woman's vagina. The motile sperm then move through the cervix, uterus, and into the fallopian tubes to fertilize the egg. Because many men with SCI are not able to ejaculate during sexual intercourse, they and their partners should be informed of other methods that may be necessary to achieve pregnancy. Some couples may find success in achieving pregnancy with in-home insemination if masturbation or RPE can induce ejaculation. This process involves collecting semen to be drawn into a syringe without a needle; the syringe is inserted into the vagina; and the semen is squirted into the vagina near the cervix. If in-home insemination is not successful, couples can choose from other medically assisted procedures to achieve pregnancy. One procedure requires doctors to separate the sperm from the semen and insert the sperm into the uterus. This process is called Intrauterine Insemination (IUI). This procedure improves the chances of the sperm traveling into the fallopian tubes to fertilize the egg. Other medical procedures involve fertilizing the egg outside the woman's body. After fertilization occurs, pregnancy is achieved through either In vitro Fertilization, Gamete Intrafallopian Transfer, Blastocyst Transfer, or Intracytoplasmic Sperm Injection.

**Conclusion**

It is important for men with spinal cord injury and their partners to know that they may face challenges in achieving pregnancy. Those challenges may be with erectile function, ejaculatory function, AD and/or low semen quality. In fact, there is simply no way to predict what, if any, challenges men with SCI and their partners may face in achieving pregnancy. However, there are options available to overcome those challenges. It may take time, and there is no guarantee for success. But couples that work together can become parents.

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**Note**

This article was written by the editor and includes content taken from "A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction" by Maria J. Amador, BSN, CRRN, Charles M. Lynne, MD, Nancy L. Brackett, PhD, HCLD. It is a publication funded by the Paralysed Veterans of America SCI Education and Training Foundation. To receive a copy of this booklet, contact: The Miami Project to Cure Paralysis

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Telephone: (305) 243-7108 Facsimile: (305) 243-6017
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This column provides an update of current research being conducted by the UAB Rehabilitation Research and Training Center on Secondary Conditions of Spinal Cord Injury. The work is supported by grant #H133B980016 from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Dept. of Education, Washington, DC.

Indirectly, individuals with spinal cord injury (SCI) are at an increased risk for obesity and related hypertension, dyslipidemia, diabetes mellitus, cardiovascular disease, obstructive pulmonary disease, and certain cancers. However, very little research has been done to develop any weight management program that is safe, effective and specifically for individuals with SCI. It is believed that such a program would need to use a combination of dietary management and exercise to be effective in helping to prevent obesity and other health problems.

Objectives

EatRight is a weight management program designed at the University of Alabama at Birmingham (UAB) for the general population. It is a 12-week program that includes diet instruction, behavior modification support, and exercise.

This research project aims to create a similar program specifically designed for individuals with SCI. This EatRight for SCI program will seek to teach individuals with SCI to effectively manage their body weight and improve their nutritional status and overall health.

The specific aims of this EatRight for SCI are:

1. to understand the food preferences, eating habits, and nutritional and health status among persons with SCI, particularly those who are overweight;
2. to identify the associated factors for overweight. These factors include demographic and injury-related variables, lifestyle characteristics, weight history, and psychosocial factors;
3. to modify the existing EatRight weight loss program for the special nutrition needs and metabolic characteristics of individuals with SCI;
4. to preliminarily execute the revised EatRight for SCI weight management program in a small sample of community-residing persons with SCI;
5. to make further revisions if indicated by the pilot test;
6. to examine the effectiveness and safety of the finalized EatRight for SCI program regarding the improvement in dietary habits, physical activity, weight control, body composition, nutritional status, general health, and psychological well-being; and
7. to identify the contributing factors for the success in weight management among individuals with SCI who participate in the EatRight for SCI program.

Methods

The EatRight for SCI program is to be created in 3 phases:

1. EatRight emphasizes a low fat diet. This program will need to be modified for individuals with SCI. The EatRight for SCI program will emphasize adequate intakes of protein, fiber, and fluid for improving or maintaining skin integrity, bowel function, and urological status. The other components of the original EatRight program such as behavior modification, stress management, and exercise session will also need to be modified for individuals with SCI.

2. The EatRight for SCI program will first be pilot tested on a small number of people. The results will be used to improve the effectiveness of the program. The participants will have to be 1) injured for more than 1 year, 2) between 20 and 65 years old, 3) generally healthy without significant medical problems, 4) without a special need for dietary attention and preparation (i.e., without ventilator-dependence, dysphagia, or enteral feeding), 5) ready for diet change and weight control.

Note

The 12-week series of nutrition classes, exercise sessions, and sample menus are free to participants. All participants must be able to attend classed once every week. Transportation service is available upon request. To get a free evaluation to see if you qualify to participate in the EatRight for SCI program, contact Dr. Yu-ying Chen at yychen@uab.edu or 205-934-3329.
control, and 7) able to provide written consent.

3 A total of 20 individuals with SCI will participate in EatRight for SCI, a program based on the EatRight weight management program. The study will test the safety and effectiveness of EatRight for SCI.

Conclusion

Diet and exercise are believed to be a safe and cost-effective way to prevent and treat obesity and improve overall health. For individuals with SCI who are at risk for obesity, a weight management program that combines dietary instruction, tips for increased physical activity, and a home-based exercise program can be of great benefit in preventing secondary complications and improving wellness.

Some Activities Include:
♦ speakers from UAB discuss current research in SCI;
♦ representatives from community agencies share the latest information on recreational activities, independent living, job training and placement, and current back-to-work incentives;
♦ specialty equipment suppliers display information on wheelchairs and assistive technologies as well as offer hints and demonstrations on wheelchair maintenance; and
♦ creative art exhibits by persons with SCI.

Pre-registration is required!
Deadline is July 13, 2001

Registration begins at 9 am with activities scheduled from 10 am to 4 pm. You can pre-register online for this free 1-day event at www.spinalcord.uab.edu/show.asp?durki=37184, or clip this form, complete the registration information below and send it to the address provided.

Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
Phone 205-934-3283 Fax 205-975-4691
Email scirtc@sun.rehabm.uab.edu

Registration Information

Name __________________________
Address __________________________
City_________________________State____ Zip_____
Email __________________________
Phone (day) _______________ Fax ____________

# attending with you _____ Relation ____________
Do you wish us to reply by Mail ____ Email ____ Fax ____

Women

Advanced planning and preparation will help prevent some problems. Consult your doctor before becoming pregnant to determine if any changes in medication will be needed because some medications can be harmful to the fetus. Interview obstetricians in your neighborhood and find out which doctor has experience with women with SCI. Then, take a team approach to your pregnancy. Make sure that your obstetrician consults a physiatrist (doctor specializing in rehabilitation medicine) on issues such as AD, bowel and bladder management, and pressure sores.

Parenting is a team effort. You can share responsibilities to help make your pregnancy manageable. As with Angeline and Melissa, their husbands played important roles in modifying their home. Some women may also have support from their friends and relatives when needed. You may even have times when you need help from others. Most people are willing to help when they know what needs to be done.

It is important to remember that the opportunity for marriage, family, and happiness is available for everyone. Sometimes the approach must be different, but the path is accessible. Anything is possible with a good attitude and the right planning and preparation. Angeline and Melissa are two real life examples.
SCI Health Education Multimedia Series - UAB has a series of slideshows available FREE on computer CD. Current topics include *Functional Goals Following SCI, Prevention of Pressure Sores Through Skin Care, and Prevention and Treatment of UTI*. Call 205-934-3283, email rtc@uab.edu, or go to www.spinalcord.uab.edu/show.asp?durki=28921 for more information.

*Pushin' On* and other information on SCI is also available on the SCI Information Network web site at www.spinalcord.uab.edu and the *Fax Information System* at 205-975-8376.

**SCI Email Distribution** - You can be notified via email as new and updated SCI material from UAB becomes available; email scirtc@sun.rehabm.uab.edu and type, "subscribe to SCI email distribution list."

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**Resources**

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**Web Resources**

- SCI Health Education Multimedia Series - UAB
- Male Fertility & Sexual Functioning
- Parenting
- Weight Management

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**Pregnancy**

- www.spinalcord.uab.edu/show.asp?durki=21598

**Male Fertility & Sexual Functioning**

- www.pn-magazine.com/pn/articles/kids.htm
- www.spinalcord.uab.edu/show.asp?durki=21839
- www.spinalcord.uab.edu/show.asp?durki=21699

**Parenting**

- www.beachcenter.org/
- www.lookingglass.org/parent.htm

**Weight Management**

- www.lsi.ukans.edu/rtcil/pvadecon.htm
- www.spinalcord.uab.edu/show.asp?durki=21583
- www.craighospital.org/C_Research/c10b_fat.html
- www.craighospital.org/C_Research/c2g_cholesterol.html
- www.craighospital.org/C_Research/c2w_weightGain.html

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**2 Month Study in Reducing UTIs** - Individuals with SCI over 19 years of age and in reasonably good health are needed to evaluate three solutions for bladder irrigation to determine which is most effective in reducing UTIs. Participants must use Foley or Suprapubic method of bladder management. For more information, contact Kay Canupp at 934-0355.

**Are You Pregnant?** - UAB is looking for women with SCI who have just become pregnant to participate in a video program documenting the process of pregnancy after injury. Compensation up $1,125. For details, contact Phil Klebine or Linda Lindsey at rtc@uab.edu or 205-934-3283.