

PREGNANCY AND SPINAL CORD INJURY/ DISORDER (SCI/D)

A CONSUMER GUIDE
2026 EDITION



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Pregnancy and Spinal Cord Injury/Disorder (SCI/D)
A Consumer Guide

2026 Edition

We thank those who gave time and effort to this project for sharing their expertise willingly to enhance the lives of those with spinal cord injury or dysfunction. We would also like to thank all of the contributors to past versions of this manual.

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SCOPE OF THIS GUIDE

This consumer guide provides an overview of pregnancy planning, pregnancy care, birth preparation, and postpartum considerations for people with spinal cord injury or disorder (SCI/D). It is designed to help individuals with SCI/D, their families, and care partners understand common pregnancy-related changes, anticipate SCI/D-specific risks, and prepare for conversations with their medical and rehabilitation teams.

This guide **includes** general education on:

- Pre-pregnancy counseling, fertility awareness, contraception considerations, and pregnancy planning
- Building a multidisciplinary care team
- Healthcare access
- Expected pregnancy changes
- SCI/D-specific concerns during pregnancy
- Labor and delivery planning
- Postpartum recovery, infant-care adaptation, therapy follow-up, emotional health, and fourth-trimester SCI/D considerations

This guide **does not** provide individualized medical advice, diagnose conditions, prescribe treatment, or replace care from a qualified healthcare professional. Pregnancy with SCI/D should be managed in partnership with clinicians familiar with both obstetrics and SCI/D-related care.

This guide also **does not attempt to serve as a complete manual for sexual function, fertility treatment, contraception, durable medical equipment, or adaptive sexual health products.** See the *ASIA Durable Medical Equipment* manual for a section on DME related to sexual function.

HOW TO USE THIS GUIDE

- Thinking about pregnancy: Start with Sections 1–2 (Pre-Pregnancy Counseling and Preconception Evaluation).
- Already pregnant: Review Sections 3–5 (Health Care Access, What to Expect During Pregnancy and SCI/D Specific Medical Concerns).
- Preparing for birth: Focus on Section 6 and 8 (Labor and Delivery Planning and Support Providers).
- After birth: See Section 7 (Fourth Trimester/Postpartum).
- Abbreviations - see appendix

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SECTION 1

PRE-PREGNANCY COUNSELING: FERTILITY EDUCATION AND PLANNING

1A. Understanding Fertility and Sexual Function after SCI/D

Sex and fertility can change after a spinal cord injury or disorder. Changes in feeling, muscle tightness, bladder and bowel routines, and medications can affect comfort and pleasure. There are many ways to adapt positions and routines so that sex and pregnancy planning still feel safe and satisfying.

Even with changes, many people with SCI/D can become pregnant and have healthy pregnancies. It has been reported that up to 14% of women of reproductive age with SCI become pregnant after their injury.¹ Importantly, having a



SCI does not prevent pregnancy from occurring naturally—the uterus and ovaries typically function normally. If you have questions about sexual function, fertility, or contraception, discuss them early with your healthcare team.

Adaptive equipment for intimacy is beyond the scope of this document, but can be found in the ASIA Guidelines for use of Durable Medical Equipment for Persons with Spinal Cord Injury and Dysfunction and online support communities.

1B. Family Planning and Pregnancy Spacing

Topics to discuss before trying to conceive:

- Contraception and sexual education (including immediately after SCI/D)
- Timing of conception—for example, waiting until medical conditions and daily routines are stable
- Pregnancy spacing and future family planning goals

1C. Accessibility and Environmental Planning

Planning ahead can reduce barriers to care and improve safety during pregnancy. See Section 3 for more information about accessibility in the healthcare setting.

- Identify reliable and accessible transportation options
- Assess home accessibility, including bathroom setup, bed height, transfer surfaces, and space for baby care
- Plan for caregiver or partner support during late pregnancy and postpartum

1D. Health Care Logistics and Personal Preferences

- Review SCI/D-specific risks and past medical history (e.g., UTIs, AD, skin breakdown, DVT/PE, respiratory issues) with your multidisciplinary team (see 1E).
- Review all of your current medications (prescription and over the counter) to determine if they are safe to continue during pregnancy.
- Discuss preferences—vaginal delivery vs. cesarean, anesthesia options—with your OB/GYN early.
- Assemble a specialist team to discuss how SCI/D may influence pregnancy, labor, delivery, and the postpartum period.

1E. Build a Multidisciplinary Team (Including a Physiatrist)

In addition to speaking with your OB/GYN or primary care doctor, consultation with a rehabilitation physician (physiatrist) who has experience in women's health after SCI/D is strongly recommended. A physiatrist can explain what your specific SCI/D may mean for pregnancy, labor, delivery, and the postpartum period. If an OB/GYN is not already involved in your care, your physiatrist can help identify an obstetrician who has experience caring for women with SCI/D and assist with coordinating referrals.

Depending on your needs, your care team may include:

- Maternal–fetal medicine subspecialist
- Urologist
- Anesthesiologist (consult well before labor)
- Pulmonologist (lung specialist)

- Physical and occupational therapists
- Respiratory therapist
- Nurse
- Lactation consultant
- Assistive technology professional (ATP) / Certified Rehabilitation Technology Supplier (CRTS)
- Doula (see Section 8)

1F. Safety and Social Needs Screening

Pre-pregnancy counseling should include discussion of safety and access to essential resources:

- Concerns about domestic violence and personal safety
- Concerns about access to healthcare, including insurance coverage and transportation
- Concerns about access to food and shelter

SECTION 2

PRECONCEPTION MEDICAL EVALUATION AND COUNSELING

Women with SCI/D considering pregnancy should schedule a pre-pregnancy counseling visit with their OB/GYN or primary care physician (PCP). This visit provides an opportunity to review the risks and benefits of pregnancy in SCI/D, manage chronic conditions, review medications, and develop strategies to minimize health risks for you and your baby. Your physician may recommend baseline kidney and lung function assessments, as well as genetic counseling and screening. Lifestyle counseling—including nutrition, physical activity, and weight goals—and vitamins or supplements, such as folic acid, may be recommended. This visit is also an opportunity to identify barriers to accessing care and to determine who should be included on your multidisciplinary healthcare team.

2A. Baseline Health Assessment Checklist²

- Medical, surgical, and psychiatric history
- Family and genetic history
- Obstetrical and gynecological history
- Allergies
- Current medications (prescription and nonprescription)
- Current supplements
- Preventive health screenings (access and completion)
- Immunizations
- Screening for infectious diseases and exposures
- Substance use
- Nutritional status
- Ability to achieve and maintain a healthy body weight
- Exercise and physical activity

2B. Contraception

There are many options available if you want to prevent or delay pregnancy. It is important to discuss these with your OB/GYN, taking into account your level of injury, hand function, and any SCI/D-specific risks for use.

Barrier or Device-Based Methods

These include condoms, intrauterine devices (IUD), and diaphragms.

- When selecting a method, talk to your provider to determine the best type of barrier for you. Consider your hand function and talk to your partner or caregiver to determine the assistance that you may need for use.
- IUDs (intrauterine device) and diaphragms may carry an increased risk for pelvic inflammatory disease (PID) and uterine or vaginal erosion. If you have decreased sensation in your pelvis, symptoms may be less noticeable, so it is important to review monitoring strategies and symptoms of infection with your provider, and when to seek care.
- Condoms also reduce your risk of sexually transmitted infections (STIs).

Oral and Hormonal Contraceptives

- Individuals with SCI/D may have a higher baseline risk for clotting. Hormonal contraceptives containing estrogen can further increase the risk of blood clots or stroke so options should be discussed carefully with your OB/GYN.
- Some injectable forms of this medicine may increase your risk of bone loss if you use them for a long time. Your health care provider will consider this risk before you start treatment. They may also recommend a test to check your bone health before you begin.
- If you take medications like anti-seizure drugs or certain antibiotics, they can make some forms of birth control less effective. Always tell your provider about all your medications when choosing birth control.
- Long-acting reversible birth control (LARC), such as an implant or an IUD, works very well and does not need daily care. If you have SCI/D, LARC may be a good choice, especially if it is hard to remember to take a pill every day, go to regular appointments, or use your hands for some tasks.

SECTION 3

HEALTH CARE ACCESS, APPOINTMENTS, EQUIPMENT, AND THERAPY (SET UP EARLY)

Pregnancy means you will have more health care visits, and your needs may change over time. It is helpful to find health care providers and support that meet your needs as early as possible. If you can, do this before you become pregnant or during the first 3 months of pregnancy.

3A. Preparing for Medical Appointments (Call Ahead)

To support a successful appointment, consider contacting the clinic before your visit to share relevant information, ask questions about accessibility, and, if available, request a tour of the facility.

Helpful information to share includes:

- Type and width of your wheelchair or mobility device.
- Equipment or assistance needed for transfers and positioning.
- Whether you may need a longer appointment.

Questions to Ask About Parking	Comments/Notes
If there is a parking structure, what is the clearance height?	
If payment for parking is required, is there an attendant, or there are self-pay machines by the building entrance?	
Is there accessible parking near the accessible entrance to the building?	
Is there adequate room next to the parking spot for a wheelchair ramp or for transfers out of a vehicle?	
Are parking areas, walkways, and entrances covered for weather protection?	

Questions to Ask About Office Entry and Waiting Room	Comments/Notes
Are there automatic doors at exterior and interior entrances?	
Do doors have lever handles?	
Is the front entrance accessible with a ramp and curb cut? If not, where is the accessible entrance?	
Are doorways to the office, bathrooms, and exam rooms at least 32 inches wide?	
If hallways are narrow, what is the width of the path leading to the door?	

Questions to Ask About the Bathroom	Comments/Notes
Is there space to position a wheelchair beside the toilet?	
Is there a grab bar near the toilet?	
Are shelves and specimen cabinets within reach from a seated position?	
Is there open space under the sink, and what is the sink height?	
Is there enough space for a 5-foot turning radius?	
If the bathroom is inaccessible, can I collect a urine sample at home?	

Questions to Ask About Exam Rooms and Diagnostic Equipment	Comments/Notes
Is there enough space next to the exam table or chair to accommodate a wheelchair (approximately 2.5 ft x 4 ft)?	
Is there a height-adjustable exam table or chair (recommended 17–19 inches)? Can it be reserved for my appointment?	
Will additional staff be available to assist with transfers, or should I bring someone?	
If I bring a lift, is there enough space for the lift (including under the exam table) and wheelchair?	
Is there an accessible scale? How do you recommend I be weighed?	
Can mammography equipment accommodate seated positioning? If not, what modifications are possible?	

3B. Accessible Medical Examination Tables and Chairs

Fixed-height exam tables (commonly 32 inches) can be a barrier for safe transfers. The recommended transfer surface range is 17 to 19 inches from the floor.³ If a height-adjustable table is not available, plan ahead for transfer assistance—options may include a manual lift or a two-person assisted transfer. Consider how your transfer needs may change as pregnancy progresses.

For more information: Accessible Medical Examination Tables and Chairs | ADA National Network (adata.org)



3C. Scales and Weight Monitoring

Prenatal care includes regular weight monitoring, but many offices do not have accessible scales. Ask about accessible weighing options, as your weight is an important part of prenatal care. Options include:

- **Wheelchair platform scales** (clinic or hospital purchase; approximately \$300–1,000+). Ideal for individuals with mobility or balance challenges.



- **Digital chair scales** (clinic purchase; approximately \$800, e.g., Health O Meter).

- **Bed scales** (hospital use).

- **Home option:** if you use a Hoyer lift, a digital hanging scale can help track weight between visits (discuss with your physician). Various options available for under \$100.



- Skin monitoring strategies and wound prevention
- Transfer and mobility strategies across trimesters
- Recommendations and prescriptions for additional equipment

Occupational Therapy (OT) may help with:

- Wheelchair fitting and adjustments as weight and body shape change
- Cushion evaluation (including weight capacity) and seating consultation
- Home modifications and equipment recommendations
- Strategies to maintain independence as changes occur in activities of daily living (ADLs) and instrumental activities of daily living (IADLs)
- Bladder program adaptations, including catheterization strategies and adaptive equipment
- Infant care strategies, including positioning, feeding, carrying in a wheelchair, and transfers while holding a baby
- Adapted baby equipment and setup (e.g., changing station modifications, high chairs, clothing adaptations)

Home Exercise Program

- Individualized strategies to help return to baseline function after delivery (when cleared by your doctor).
- General activity guidance recommends at least 150 minutes per week of moderate-intensity aerobic activity, adapted to your body and SCI/D (refer to DME manual for further information).

Safety Adaptations

- **Shower Equipment:** A shower transfer bench can make it easier and safer to get in and out of the tub. You can sit on the bench first, then slide into the tub, allowing for a shorter transfer. This may be especially helpful as your weight and body shape change during pregnancy or if you have more muscle spasms.
- **Raise Your Sofa:** If your sofa is too low, sturdy furniture risers or blocks can make it higher. A higher seat can make it easier to move between your wheelchair and the sofa. This can help during the later months of pregnancy and while you recover after birth.
- **Lower Your Bed:** If your bed is too high, removing the box spring or using a lower bed frame can make it easier to get in and out of bed. A lower bed may help you stay more independent as your balance and movement change during pregnancy.

3D. Physical and Occupational Therapy (PT/OT) Referrals

As pregnancy progresses, PT/OT can help address functional changes, equipment needs, home modifications, and safe strategies for caring for a baby. Early referrals — before significant functional changes occur — are recommended.

Physical Therapy (PT) may help with:

- Developing an exercise program to manage changes in spasticity, weight and body shape
- Respiratory exercises as breathing may change

SECTION 4

WHAT TO EXPECT DURING PREGNANCY

4A. Normal Pregnancy: An Overview

Pregnancy involves changes in virtually every organ system over approximately 40 weeks. These changes are driven by hormonal shifts—primarily rising levels of human chorionic gonadotropin (hCG), progesterone, and estrogen—and by the physical growth of the uterus and baby. Understanding what is typical in pregnancy helps you and your care team recognize when something may need closer attention.

Common pregnancy experiences (with or without SCI/D) include:^{4,5}

- Fatigue and changes in sleep
- Nausea, vomiting, and food aversions (especially in the first trimester)

- Headaches and dizziness
- Nasal congestion
- Shortness of breath (especially later in pregnancy)
- Hormonal mood changes
- Weight gain
- Growth of the uterus and shifts in center of gravity
- Frequent urination
- Heartburn and indigestion
- Hemorrhoids
- Constipation
- Body aches and pains
- Numbness and tingling in the arms and legs
- Swelling in the feet and ankles

4B. Trimester-by-Trimester Expectations

The sections below describe what is typical in each trimester of pregnancy. People with SCI/D experience these same changes, but SCI/D can affect how they feel, how they are recognized, and what additional considerations may apply. Each section highlights key SCI/D-specific differences.

Trimester	Common Symptoms (General Population)	SCI/D Considerations
First (Weeks 1–12)	Fatigue, nausea/vomiting (morning sickness), breast tenderness, frequent urination, mood changes, headaches, constipation, bloating.	Bladder frequency and leaking may begin or worsen earlier. Constipation may compound existing neurogenic bowel issues. Some people may also experience nausea or vomiting, which can be hard to tell apart from certain nervous system reactions that can occur with higher-level spinal cord injuries. Spasticity triggers may increase.
Second (Weeks 13–27)	Often improved energy, growing abdomen, heartburn/reflux, constipation, hemorrhoids, back/pelvic discomfort, swelling may begin, fetal movement.	Center of gravity shifts — transfers, wheelchair propulsion, and balance may feel different. Skin breakdown risk increases with weight gain. Monitor blood pressure: preeclampsia (see section 5B) and AD can both emerge in this trimester.
Third (Weeks 28–Birth)	Increased fatigue, shortness of breath, more reflux/constipation, swelling, sleep disruption, Braxton Hicks contractions.	AD risk is highest in this trimester and during labor. Respiratory function may be significantly compromised at higher injury levels. Monitoring for early/undetected labor becomes critical after 28 weeks. Equipment needs often peak.

First Trimester (Weeks 1–12) — What Is Happening in Your Body

Rising hormone levels drive early pregnancy symptoms. hCG peaks early and contributes to nausea. Progesterone relaxes smooth muscle throughout the body, slowing digestion and contributing to constipation and bloating. Blood volume begins to expand, and heart rate increases slightly. These vascular changes can cause headaches and dizziness.

For people with SCI/D, nausea and fatigue may feel more intense if they compound symptoms already present from the injury. Because progesterone affects the bladder and bowel as well, constipation and changes in bladder function may be noticeable early. This is a good time to establish all members of your care team, discuss any medication changes, and begin monitoring for SCI-specific complications.

Second Trimester (Weeks 13–27) — What Is Happening in Your Body

Many people feel better as hCG levels stabilize. The uterus becomes visible above the pelvis, and the abdomen begins to grow noticeably. Cardiac output increases significantly to support the growing placenta and fetus. The center of gravity shifts forward, which may affect balance and movement. Heartburn may increase as the growing uterus pushes upward on the stomach. Fetal movement is typically first felt between weeks 16 and 22.

For people with SCI/D, the shift in center of gravity can significantly affect wheelchair propulsion, transfer techniques, and balance. The risk of skin breakdown increases as weight increases and pressure points change. It is important to know your personal baseline blood pressure as blood pressure may rise during pregnancy. Cervical checks and monitoring for preterm labor become relevant in the latter part of this trimester.

Third Trimester (Weeks 28–Birth) — What Is Happening in Your Body

The baby's growth accelerates, and the uterus presses on surrounding organs, including the diaphragm, bladder, and major blood vessels. Shortness of breath, heartburn, urinary frequency, and swelling are common. Braxton Hicks (practice) contractions may occur. The body begins producing relaxin, loosening ligaments and joints in preparation for delivery.

For people with SCI/D, this is the highest-risk trimester for SCI/D-specific complications. Autonomic dysreflexia (AD) risk increases significantly and is highest during labor. Breathing may be significantly compromised at higher injury levels, and a consultation with a pulmonologist may be recommended. Detecting labor can be very difficult. Weekly cervical exams beginning around 28 weeks are often recommended. Mobility, transfers, and bladder and bowel care typically become most challenging during this trimester.

SCI/D-SPECIFIC MEDICAL CONCERNS DURING PREGNANCY

Pregnancy is considered high risk for people with SCI/D because it can worsen many existing conditions. Research shows that women with SCI/D have significantly higher rates of several complications compared to women without SCI/D, including urinary tract infections (over 26 times the risk), blood clots (over 9 times the risk), and preterm rupture of

membranes (about 2 times the risk).^{4,6,7,8} This does not mean pregnancy is unsafe or not possible. With early planning and a knowledgeable team, most pregnancies in women with SCI/D result in healthy mothers and babies. It does mean that close monitoring and early planning are essential.⁹

The sections below describe SCI/D-specific concerns, when they are most likely to occur, and how to manage them.

SCI/D Complication	Approximate Risk / When Most Likely	Key Action
Urinary tract infection (UTI)	~59% of pregnancies; can occur any trimester	Screen early; treat promptly
Autonomic dysreflexia (AD)	~27%; risk highest in 3rd trimester and labor	Know your baseline BP; have a plan
Worsened spasticity	~22%; can occur any trimester	Identify/treat triggers
Deep vein thrombosis (DVT/PE)	~8%; risk elevated throughout but highest late pregnancy/postpartum	Monitor; discuss prevention with your doctor
Postpartum depression	~35%; postpartum (up to 8x risk vs. general population)	Screen prenatally; plan postpartum support
Preterm delivery / preterm rupture of membranes	About 2x risk vs. general population	Weekly cervical checks from ~28 weeks
Pressure injuries (skin breakdown)	Throughout pregnancy; risk rises with each trimester	Frequent skin checks; adjust body position or shift your weight

Sources: ACOG Committee Opinion (2020); McLain et al. (2023); Ghidini et al. (2008); Robertson & Ashworth (2022).

What it is: Autonomic dysreflexia (AD) is a sudden, dangerous spike in blood pressure caused by something bothering the body below the level of injury. It most commonly affects people with injuries at or above T6 but can be seen at lower levels of injury. It is the most serious SCI-related complication during pregnancy.

When it is most likely: AD can occur at any point during pregnancy, but risk is highest in the third trimester and during labor. Approximately two-thirds of pregnant women with SCI at or above T6 experience AD during labor. New-onset AD can also develop during pregnancy in people who have not experienced it before, sometimes as early as the

second trimester, as the uterus expands and bladder pressure increases.¹⁰

Signs and symptoms of AD include: sudden severe headache, flushing, nasal congestion, nausea, anxiety, sweating, piloerection (goosebumps), tremor, increased spasticity, elevated blood pressure, and changes in heart rate.

Important note on blood pressure: People with SCI/D typically have lower baseline blood pressure than the general population. A blood pressure reading that looks “normal” on a standard chart may represent a significant and dangerous rise from your personal baseline. Know your typical blood pressure and inform your entire care team. A

rise of 20–40 mmHg above your baseline systolic blood pressure (top number in BP reading) may require urgent evaluation for AD. For example: if your usual blood pressure is 90/60, a reading of 120/80 may be dangerous for you, even though it looks ‘normal’ on a chart. If you suddenly get a pounding headache, flushing, or feel ‘off,’ check your blood pressure right away or get help.

Key actions:

- Know and document your baseline blood pressure
- Ensure all team members—including hospital staff—can

- recognize AD and know your typical baseline blood pressure
- Have a written plan to manage AD if it develops.^{4 5} Discuss this with your OB/GYN and physiatrist
 - Keep a log to identify personal triggers and address them promptly
 - Epidural anesthesia during labor significantly reduces AD risk and is the recommended approach for women with SCI at or above T6. Speak to your anesthesiologist for further information.

AD Can Look Like Common Pregnancy Symptoms

Several normal pregnancy experiences can mimic AD. Context and blood pressure measurement are essential.

Symptom	Normal Pregnancy Cause	When to Suspect AD Instead
Nasal congestion	Hormonal changes — affects ~30% of pregnant women ¹¹	If blood pressure is above your baseline, suspect AD. If nasal congestion is experienced with blood pressure that is in a normal range for each individual, a physician should be consulted for safe symptom management options.
Sweating / feeling warm	Core body temperature rises slightly in pregnancy (0.2 degrees Fahrenheit above her normal pre-pregnancy temperature) ¹²	Sweating with elevated BP and other AD symptoms = seek evaluation
Headache ¹³	Vascular changes and blood volume expansion	Headache with any of the following warrants immediate medical attention:
Migraines (type of recurrent headache often with nausea, sensitivity to light and sound) - occurs in 1-10% of pregnant women, can increase in frequency.	Natural hormonal changes	• Head trauma • Elevated BP • New neurologic symptoms (numbness, weakness, difficulty thinking, visual changes, fever, seizures) • Changes with positioning (e.g. lying to sitting)
Tension Type Headaches (common type of headache feeling like a band around the head, scalp, or neck) - may improve or become less frequent		
Low blood sugar symptoms (in gestational diabetes)	Nausea, sweating, dizziness (can vary, and mimic symptoms of AD)	Check blood glucose and blood pressure if in doubt. Testing for gestational diabetes is performed during weeks 24-48. Education for those with gestational diabetes is vital.

As changes are noticed in how you feel during pregnancy, it is important to stay in close communication with your multidisciplinary team. They can help discern when the situation requires additional attention and when you can rest easy.

5B. Hypertension (High Blood Pressure) and Preeclampsia

Talk with your health care provider if you have high blood pressure during pregnancy. The blood pressure numbers used to diagnose high blood pressure are based on people without SCI/D. Many people with SCI/D have lower blood pressure than people without SCI/D because of changes

in the nervous system. Your provider will consider this when determining what is normal and abnormal for you when checking your blood pressure.

Home blood pressure monitoring may be recommended. Measure at the same times and in the same position each day, and keep a log.

Types of Hypertension	When / Description	What to Do
Chronic (essential) hypertension	Before 20 weeks; pre-existing high blood pressure	Discuss management with your OB/GYN early
Gestational hypertension	After 20 weeks; new high BP without other features	Requires monitoring and may require treatment
Preeclampsia	After 20 weeks; new high BP + protein in urine ± other findings. Diabetes, obesity, and prior high BP increase risk.	Requires close medical management — can affect kidneys, cause seizures, and affect the fetus
White coat hypertension	Any time; blood pressure elevated only in clinic due to stress	Home monitoring helps identify this pattern
Autonomic dysreflexia (AD)	Any time with trigger; most common in 3rd trimester and labor. AD has a stimulus (e.g., contractions, full bladder). Preeclampsia is often unpredictable and is associated with abnormal lab results.	Identify and remove trigger; follow AD management plan; contact medical team

5C. Orthostatic Hypotension (Low Blood Pressure When Upright)

Many people with a spinal cord injury or disorder (SCI/D) have a drop in blood pressure when they move from lying down to sitting up or from sitting to standing. This can make them feel dizzy or lightheaded. During pregnancy, these symptoms may get worse because pregnancy causes normal changes in blood flow and blood volume.¹⁴

Management strategies:

- Move slowly and cautiously when changing positions.
- Reposition frequently throughout the day
- Eat smaller, more frequent meals
- Stay well hydrated
- Avoid very hot showers or baths
- After about 20 weeks, dizziness when lying flat may develop due to uterine pressure on blood vessels; try lying on your left side
- Discuss additional options (compression garments, medications) with your physician

5D. Bladder Management

Urinary Urgency, Frequency, and Incontinence

As the uterus grows, it puts direct pressure on the bladder. This increases urgency, frequency, and leaking in all pregnant women and may be particularly pronounced for people with SCI/D who have neurogenic bladder.

If you use intermittent catheterization (IC) and notice more leaking between catheterizations, increased spasms, episodes of autonomic dysreflexia (AD), or larger amounts of urine when you catheterize, you may need to catheterize more often. If you use a Mitrofanoff or suprapubic catheter (SPT), you may also notice changes or challenges with bladder emptying during pregnancy. Talk with your urologist about any new symptoms, changes, or concerns so they can help you manage your bladder care.

If frequent urination is difficult to manage or leaking continues, talk with your healthcare provider about whether an indwelling (Foley) catheter may be an option. A Foley catheter has benefits and risks. For example, it may help reduce ongoing leakage, but it can also increase the risk of

urinary tract infections. Your healthcare provider can help you weigh the options and choose what is best for you.

As pregnancy progresses, positioning for bladder care may become more difficult—an occupational therapist can help you adapt your technique. You may also consider an indwelling catheter for a period of time.

Urinary Tract Infection (UTI)

The risk of urinary tract infections (UTIs) is much higher during pregnancy for people with SCI/D. If a UTI is not treated, it can lead to a kidney infection or may increase the risk of early labor. Talk with your healthcare provider about ways to prevent UTIs and report any signs of infection right away.^{4,5} Screening for bacteria in the urine (even without symptoms) is recommended early in pregnancy.

Report any new symptoms to your healthcare provider right away, including fever, increased spasticity, leaking between catheterizations, episodes of autonomic dysreflexia (AD), or foul-smelling urine. These may be signs of a urinary tract infection (UTI).

UTI symptoms can be hard to tell apart from normal pregnancy changes, such as making more urine, needing to urinate more often, or changes in urine color. If you are unsure whether a symptom is related to pregnancy or a possible infection, contact your medical team for guidance.

Your healthcare provider may recommend a urine test to check for infection based on your symptoms. Talk with your healthcare provider about your test results and symptoms to decide whether treatment, such as antibiotics, is needed.

5E. Bowel Management

Hormonal changes during pregnancy can slow down the movement of food through the digestive system, which increases the risk of constipation. This can be more challenging for people with SCI/D who may already have a neurogenic bowel. Iron supplements that are often recommended during pregnancy can also change bowel patterns and may cause constipation or diarrhea.

Review your bowel program regularly throughout pregnancy and adjust as needed.

- **If constipated:** Ask your physician about increasing water intake, dietary fiber, stool softeners, or laxatives. Digital stimulation or medications that were not previously needed may become necessary.
- **Diarrhea:** Notify your physician. Diet, medications, and your bowel program may need adjustment.

- **Hemorrhoids:** Common in pregnancy and can trigger AD and spasticity in SCI/D. Discuss pregnancy-safe topical treatments with your physician.
- **If you have a colostomy:** Abdominal stretching can affect stoma function and fit—monitor closely.
- As your body changes and grows during pregnancy, finding comfortable and effective positions for bowel care may become more difficult. An OT can provide recommendations and help you find strategies that work best for you.

5F. Deep Venous Thrombosis (DVT) and Pulmonary Embolism (PE)

Both SCI/D and pregnancy increase the risk of blood clots, including deep vein thrombosis (DVT). A pulmonary embolism (PE) happens when a blood clot travels to the lungs and can be life-threatening. Pregnant people with SCI/D have a higher risk of developing blood clots (DVT/PE) compared with pregnant people without SCI/D. This increased risk is related to changes in the body during pregnancy, including higher estrogen levels and slower blood flow in the veins.^{4,7}

Signs that may suggest a DVT (rather than typical pregnancy swelling) include:

- Redness or skin discoloration over the affected area
- Pain or tenderness
- One leg that is significantly more swollen than the other
- Swelling that does not improve with leg elevation

Seek emergency care for sudden or severe shortness of breath, which may indicate a pulmonary embolism. Discuss clot prevention strategies with your medical team.

5G. Swelling / Lower Leg Edema

Leg swelling is common during pregnancy because extra fluid can collect in the legs and the growing uterus can put pressure on blood vessels. However, it can be difficult to tell the difference between normal pregnancy-related swelling and swelling caused by a deep vein thrombosis (DVT). Watch for the warning signs listed above and contact your medical team if you have any concerns.

- Talk with your medical team about whether graduated compression stockings are right for you.
- Range-of-motion exercises, elevating your legs, and lying on your left side (if comfortable) may help improve circulation. These strategies can reduce pressure on blood vessels and help blood return to your heart.

- Swelling along with high blood pressure can be a sign of preeclampsia, a pregnancy-related condition that needs medical attention. Contact your healthcare provider if you notice these symptoms.

5H. Skin Integrity

Skin breakdown is an important concern during pregnancy, especially for people with SCI/D. Several changes during pregnancy can increase the risk, including weight gain that adds pressure to bony areas, changes in body shape that affect how pressure is distributed, increased moisture from urinary leakage, and more difficulty with repositioning as pregnancy progresses.

- Increase skin check frequency — enlist caregiver or family support
- Increase the frequency of pressure relief; discuss specific strategies with PT/OT
- Ask about wheelchair pressure mapping during pregnancy—pressure points will change
- Monitor clothing fit; tight waistbands or ill-fitting garments can cause pressure injuries and trigger AD or spasticity
- Include skin checks as a part of regular prenatal exams—advocate for this with your OB/GYN.

5I. Weight Gain

Weight gain is a normal and healthy part of pregnancy. For people with SCI/D, changes in body weight can affect mobility, transfers, equipment fit, and joint health. Planning ahead with your healthcare team can help you prepare for these changes and reduce potential challenges.

- **Mobility:** Weight gain and changes in center of gravity may make transfers and wheelchair use more difficult. Temporary equipment such as a power wheelchair, power assist device, or slide board may be needed
- **Joint pain:** Pregnancy can increase the amount of stress placed on the shoulders and arms, especially for people who rely on their upper body for mobility and transfers. Pregnancy hormones can also loosen ligaments, which may increase the risk of joint pain or discomfort. Talk with your therapist and healthcare provider about any new or worsening joint pain.
- **Equipment:** Wheelchair fit, cushions, and braces may need adjustment throughout pregnancy
- **Clothing:** Plan early for maternity clothing. Tight clothing can trigger AD, skin breakdown, and spasticity. Consider loose-fitting clothing that allows for easier access for bladder and bowel care (e.g., dresses or skirts)

5J. Spasticity

Muscle spasms and spasticity may develop or become worse during pregnancy. This affects about 22% of pregnant people with SCI/D. Talk with your healthcare provider if you notice changes in your spasticity so your care plan can be adjusted if needed.^{4,5,6,7} Several SCI/D-related complications, including urinary tract infections (UTIs), constipation, hemorrhoids, and skin breakdown, can make spasticity worse. Working with your multidisciplinary team to prevent and treat these issues can help reduce spasticity flare-ups.

- **Minimize triggers:** Keep bowel movements regular, manage hemorrhoids, check for UTIs, protect skin, speak to your healthcare provider about adding a numbing jelly to your bladder or bowel regimen
- **Track Patterns:** Consider keeping a trigger log to identify and address patterns
- **Medications:** Your treatment plan for spasticity may need to be adjusted during pregnancy and while breastfeeding. Talk with your healthcare provider about the benefits and risks of your medicines and other treatments. If your muscle spasms suddenly get worse or are difficult to control, tell your healthcare provider. This may be a sign of another problem, such as an infection.
- **Botulinum toxin (Botox):** Early research suggests that these injections may be safe during pregnancy. As with any medicine or treatment, talk with your healthcare provider about the possible benefits and risks before deciding if they are right for you.⁵
- **Non-medication options:** Stretching, positioning, braces or splints (orthotics), therapy, cold therapy, heat therapy, and exercise may be safe ways to help manage spasticity during pregnancy. Talk with your multidisciplinary team about which options are safe and right for you.
- **Intrathecal baclofen pump:** Monitor the pump site as the uterus expands. Available information on use suggests that baclofen exposure to the fetus is minimal with use, suggesting safety during pregnancy.^{6,8} If you have a baclofen pump, tell your anesthesiologist and OB/GYN before delivery. Extra planning may be needed to help protect the pump and its catheter during an epidural placement or a cesarean delivery.
- **Imaging considerations:** During pregnancy, CT scans and X-rays are avoided when possible. However, there are times when they are needed because the benefits are greater than the risks. If your healthcare provider recommends imaging, such as to check a problem with your baclofen pump, they will help you choose the safest option for you and your baby.

5K. Emotional Well-Being and Mental Health

Pregnancy brings many physical and emotional changes. It is normal to have a range of feelings during this time. Mental health is an important part of prenatal care, so screening and support should begin during pregnancy, not just after birth.

People with SCI/D may have a higher risk of postpartum depression than people without SCI/D. Talk with your healthcare provider if you are feeling sad, anxious, overwhelmed, or if your mood changes are making it hard to enjoy daily life or care for yourself and your baby.⁴

- Ask your healthcare provider about emotional health screening during your prenatal visits.
- Tell your care team early if you are feeling anxious, sad, depressed, or overwhelmed.
- Build a mental health support team during your pregnancy. This may include your healthcare providers, a mental health professional, family members, friends, or peer support.

5L. Respiratory Function

As your baby grows, especially during the third trimester, the uterus pushes up on the diaphragm. This leaves less room for your lungs to expand. For people with higher-level SCI/D, this can make breathing more difficult.

- Watch for signs of breathing problems, such as shortness of breath, trouble breathing, a faster-than-normal heart rate, unusual tiredness, headaches, poor sleep, or trouble concentrating.
- If you have a high-level spinal cord injury (cervical or upper thoracic), ask your healthcare provider if you should see a pulmonologist. They can check how well you are able to cough and clear mucus from your lungs.
- Ask your multidisciplinary team about breathing exercises that may help keep your lungs healthy during pregnancy.
- Get emergency medical care right away if you have sudden or severe shortness of breath.

5M. Neuropathy (Nerve Compression Problems)

During pregnancy, extra fluid in the body can put pressure on nerves. This may cause new numbness, tingling, pain, or weakness in the hands, wrists, arms, legs, or face. People who use a manual wheelchair may be more likely to develop hand or wrist nerve problems, such as carpal tunnel syndrome, because of the repeated use of their arms for wheelchair propulsion.⁹

- Tell your healthcare provider about any new numbness, tingling, pain, or weakness. These symptoms should be checked to make sure they are not caused by a more serious condition.
- Get emergency medical care right away if you have sudden or severe numbness or weakness that does not get better after changing positions.
- Nerve symptoms related to pregnancy often improve after delivery, but treatment may be needed to help manage symptoms during pregnancy.

5N. Fetal Growth and Positioning

Some studies suggest that pregnant people with SCI/D may be more likely to have a baby in a position that can make a vaginal birth more difficult. For example, the baby may be breech (feet or bottom first) or lying sideways (transverse position). This may be related to weakness of the abdominal muscles. The chance of these positions may be higher in people with injuries above T6.⁴ Your healthcare provider will check your baby's position during pregnancy and talk with you about the safest delivery plan.

Your healthcare team may recommend additional ultrasound scans during the third trimester to check your baby's growth, often around 28, 32, and 36 weeks. If you have SCI/D and are at risk for autonomic dysreflexia (AD), your team should monitor for signs of AD during the ultrasound because pressure on the uterus may trigger an episode.

SECTION 6

MONITORING FOR LABOR, BIRTH, AND DELIVERY

6A. Monitoring for Labor

A pregnancy is considered full term at approximately 39–40 weeks. Because signs of labor may be altered or absent, and risk of premature delivery is higher, many physicians recommend starting labor monitoring earlier—often around 28 weeks.^{4,5} This usually includes cervical checks to see if the cervix is thinning (effacement) and opening (dilation) as recommended by your OB/GYN.

6B. Recognizing Contractions and Signs of Labor

If you have reduced or no sensation below your level of injury, you may not feel contractions in the usual way. Labor contractions are regular tightening or cramping of the uterus that come and go. Over time, they usually become stronger, last longer, and happen closer together. These contractions help move your baby through the birth canal during delivery.

- If your injury level is T10 or below, you may be able to feel uterine contractions
- If your injury level is above T10, you may not feel contractions in the usual way

Signs that may suggest labor in individuals with reduced sensation include:

- Worsening spasticity
- Bladder spasms
- AD episodes
- Referred pain to the upper back or shoulders

Proactive monitoring with a home contraction monitor or extra visits to check for labor may be recommended starting at 28 weeks. Your multidisciplinary team will determine what monitoring is right for you.

If you think you might be in labor—because of any of these signs or are unsure if you are in labor—call your OB/GYN or local labor and delivery unit right away. The risks of undetected labor are serious, including the possibility of delivering far from a hospital.

6C. Autonomic Dysreflexia vs. Preeclampsia During Labor

Autonomic dysreflexia (AD) and preeclampsia can both cause dangerously high blood pressure during pregnancy and require urgent medical attention. It is important to tell the difference between them because the treatments are different.

Autonomic dysreflexia (AD): AD usually has a clear trigger, such as labor contractions, a full bladder, or a vaginal examination. Blood pressure often improves after the trigger is treated or removed.

Preeclampsia: Preeclampsia can happen without a clear trigger and is often linked with protein in the urine and changes in blood tests.

Before labor begins, make sure your entire healthcare team knows you have SCI/D and has a plan for monitoring and treating AD or other complications.

During labor, tell staff right away if you have a sudden severe headache, vision changes, or feel very unwell. Ask them to check your blood pressure and remind them that you have SCI/D.

For people with SCI at or above T6, continuous epidural anesthesia is recommended during labor. It can help manage pain and greatly reduce the risk of AD during delivery.

6D. Type of Delivery and Anesthesia Planning

- Delivery outcomes are generally similar for people with SCI/D compared with people without SCI/D. Both vaginal and cesarean births may be possible, depending on your health, pregnancy, and individual circumstances.
- Depending on your level of injury and ability to use your abdominal muscles, pushing during a vaginal birth may be more difficult. In some cases, assisted delivery with a vacuum or forceps may be considered.
- Talk with your OB/GYN early about your birth preferences and delivery plan. Planning ahead can help your care team prepare for your needs.
- Anesthesia planning should happen well before labor begins. Factors such as an intrathecal baclofen pump, previous spine surgery, or other medical considerations may affect anesthesia options. Your anesthesiologist should be involved early to help develop the safest plan for you.

6E. Incision Healing

- An episiotomy is a small surgical cut made in the tissue between the vagina and anus (the perineum) to widen the vaginal opening and help with delivery when needed.
- If an episiotomy is performed, avoid anything hot due to decreased sensation and increased risk of injury to the perineum.⁴
- Monitor any surgical sites, including a cesarean incision or episiotomy, closely for signs of infection and proper healing. If you have difficulty checking the area yourself, ask a caregiver or support person to help with skin checks.
- Ask your nurse, caregiver, or support person to look at the incision regularly and report any signs of concern, such as redness, swelling, drainage, increased warmth, or the incision starting to open.
- If your incision is not healing as expected or becomes worse over time, contact your multidisciplinary team. Your team can provide recommendations to reduce pressure on the area, improve positioning, and support healing.

6F. Exercise After Delivery

- When your healthcare provider says it is safe, consider working with a physical or occupational therapist or starting a home exercise program to help strengthen your pelvic floor and abdominal muscles. These exercises can also support balance, posture, and overall function.^{10,11}
- After delivery, therapy and exercise can help you adjust to changes in your body and improve balance, posture, transfers, and wheelchair skills as you recover.
- Ask for a physical or occupational therapy visit before leaving the hospital or soon after returning home. A therapist can help you learn safe exercises and strategies for daily activities with your baby.
- Always follow your OB/GYN's guidance about when it is safe to return to activity.

SECTION 7

THE FOURTH TRIMESTER (IMMEDIATE POSTPARTUM PERIOD)

The “fourth trimester” refers to the first 12 weeks after birth. This time includes major physical recovery, changes in hormones, disrupted sleep, emotional adjustment, and learning the new demands of caring for a baby.

7A. What Many Women Experience After Birth

For people with SCI/D, some postpartum changes may be harder to notice or may appear in different ways because of changes in sensation and function. You may also be balancing your usual SCI/D care needs, such as bowel, bladder, and skin care, while adjusting to the new responsibilities of caring for a baby.

Postpartum changes include:

- Bleeding and cramping as the uterus returns toward its pre-pregnancy size
- Breast and lactation changes (whether breastfeeding or not)
- Pelvic floor and core changes
- Fatigue and sleep disruption
- Mood changes and emotional adjustment

7B. Postpartum Mood and Depression/Anxiety

- Many new parents, including those with SCI/D, experience changes in mood after birth. These feelings are common and can happen during the adjustment to parenthood.
- People with SCI/D may have a higher risk of postpartum depression compared with the general population. Temporary mood changes, often called the “baby blues,” usually happen in the first few days after birth and are different from postpartum depression, which can develop over weeks to months.
- Seek help right away if you have thoughts of harming yourself, feel unable to care for yourself or your baby, or experience severe anxiety, panic, or feelings of hopelessness.
- Before delivery, build a support plan for your emotional health so you have help available when you need it most.

7C. SCI/D-Specific Postpartum Considerations

- After delivery, your bladder and bowel routines may need to be adjusted. If you notice new leaking, difficulty emptying your bladder, more urinary tract infections (UTIs), or changes in your bowel routine, ask your multidisciplinary team to review your routines.
- Because you may spend more time sitting while feeding or holding your baby, plan regular pressure reliefs and check your skin every day. If possible, try to shift your weight or change positions every 15–30 minutes. Talk with your multidisciplinary team about cushions or seating changes if you notice redness, skin changes, or discomfort.
- Spasticity may increase after birth due to infection, pain, constipation, or lack of sleep. If your spasms suddenly change or make it harder to care for your baby, let your multidisciplinary team know. You may need changes to your medications or therapy plan.
- Continue to watch for signs of blood clots (DVT/PE) after delivery and follow your healthcare provider’s recommendations for prevention. Contact your doctor or seek emergency care right away if you have new swelling, warmth, or redness in one or both legs, chest pain, or sudden shortness of breath.
- Plan for at least one physical therapy (PT) or occupational therapy (OT) visit within the first 6–12 weeks after delivery. A therapist can help review transfers, wheelchair setup, baby-care tasks (such as lifting, carrying, dressing, and bathing), and home safety.
- Stay connected with your healthcare team, keep follow-up appointments, and ask for help early if something does not feel right.

SECTION 8

MIDWIFERY AND DOULAS

Both midwives and doulas can provide valuable support for people with SCI/D during pregnancy, birth, and the postpartum period. Their roles are different, but they can work together as part of your multidisciplinary team.

The most important factor is finding providers who have experience with, or are willing to learn about, disability and SCI/D-specific needs. A care team that understands your individual needs can help support a safe and positive pregnancy and birth experience.

8A. Midwifery Care

If your pregnancy is considered “high risk” because of SCI/D or other medical conditions, midwifery care is often provided together with an OB/GYN or maternal–fetal medicine specialist. This team-based approach allows you to receive specialized pregnancy care while also getting the support a midwife can provide.

What a midwife does: Certified nurse-midwives (CNMs) and other trained midwifery professionals are licensed healthcare providers who can perform physical exams, order and review tests, monitor your baby’s growth and development, support labor and delivery, and provide care after birth. They are trained to care for healthy, low-risk pregnancies, recognize possible complications, and involve an OB/GYN or other specialist when needed.

Is midwifery care appropriate with SCI/D? Midwifery care may be an option for some people with SCI/D, depending on your level of injury, overall health, and any SCI/D-related complications. Many people with SCI/D receive care from a team that may include a midwife, OB/GYN, and/or maternal-fetal medicine specialist. Your healthcare team can help determine the level of specialist care needed based on your individual health needs and pregnancy risks.

Questions to ask a midwifery practice:

- Do you have experience caring for people with SCI/D or physical disabilities?
- Which hospital are you affiliated with, and do you have attending privileges there?
- How do you collaborate with OB/GYN or maternal-fetal medicine specialists when complications arise?
- Is the practice physically accessible for wheelchair users?

- How familiar are you with autonomic dysreflexia and its management?

Because pregnancy with SCI/D is often considered higher risk, many experts recommend planning for birth in a hospital rather than at home or in a freestanding birth center. A hospital setting allows your care team to respond quickly if complications occur, such as autonomic dysreflexia (AD) or breathing problems.

8B. Doula Support

What a doula does: Doulas are trained, non-clinical professionals who provide continuous emotional, physical, and informational support before, during, and after childbirth. They do not deliver babies or provide medical care. Their role is to support the birthing person and their partner—through comfort measures, advocacy, education, and continuous presence. A doula is not a replacement for medical providers.

Evidence for Doula Support

Research consistently shows meaningful benefits associated with doula care, including:

- Approximately 53% lower odds of cesarean delivery in doula-supported births^{12,13,14}
- Approximately 58% lower odds of postpartum depression and anxiety^{12,13,14}
- Reduced rates of preterm birth, labor duration, and use of pain medication
- Improved breastfeeding initiation rates
- Greater overall satisfaction with the birth experience.

ACOG and the Society for Maternal-Fetal Medicine recognize continuous support during labor as one of the most effective tools for improving labor and delivery outcomes.²⁵

How Doulas Can Specifically Help People with SCI/D

For people with SCI/D, a doula’s non-clinical role can be especially valuable:

- **Navigation and advocacy:** Doulas can help communicate preferences, needs, and SCI/D-specific information to clinical providers—particularly in hospital settings where staff may be unfamiliar with SCI/D
- **Birth plan support:** Doulas can help you develop and communicate an accessible birth plan, including

positioning strategies, AD warning signs to share with staff, and personal preferences

- **Continuous presence:** Unlike nurses and doctors who may change shifts, a doula can remain with you throughout labor—providing consistency at a time when SCI/D complications may require vigilant observation
- **Postpartum support:** Postpartum doulas can assist with non-medical newborn care, breastfeeding support, emotional recovery, and connecting families with resources—particularly when adapting to infant care with SCI/D
- Preparation for an accessible birth environment: Doulas familiar with disability can help identify accessibility needs in the birth setting in advance

Finding a Doula

When interviewing potential doulas, consider asking:

- Do you have experience supporting people with physical disabilities or SCI/D?
- Are you familiar with autonomic dysreflexia?
- How will you support me in communicating SCI/D-specific needs to hospital staff?
- What training and certifications do you have?
- Do you offer postpartum support as well?

Note: Doula services are not always covered by insurance. Some states have expanded Medicaid doula coverage—check your state’s current policies. Some community-based doula programs offer low- or no-cost services.

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- Refer to the chapters on lactation and parenting for more information during the postpartum phase.*

APPENDIX A

ABBREVIATIONS AND ACRONYMS

This appendix defines abbreviations and acronyms used in this guide, including SCI/D-specific, pregnancy-related, rehabilitation, equipment, and healthcare terms.

Abbreviation	Meaning
ACOG	American College of Obstetricians and Gynecologists
AD	Autonomic dysreflexia
ADA	Americans with Disabilities Act
ADL	Activities of daily living
ASIA	American Spinal Injury Association
ATP	Assistive Technology Professional
BP	Blood pressure
CNM	Certified nurse-midwife
CRTS	Certified Rehabilitation Technology Supplier
CT	Computed tomography
DME	Durable medical equipment
DVT	Deep vein thrombosis
PE	Pulmonary embolism
hCG	Human chorionic gonadotropin
IC	Intermittent catheterization
IADL	Instrumental activities of daily living
IUD	Intrauterine device
LARC	Long-acting reversible contraception
MFM	Maternal–fetal medicine
mmHg	Millimeters of mercury; a unit used to measure blood pressure
OB/GYN	Obstetrician/gynecologist
OT	Occupational therapy or occupational therapist
PID	Pelvic inflammatory disease
PPD	Postpartum depression
PT	Physical therapy or physical therapist
SCI/D	Spinal cord injury or disorder
STI	Sexually transmitted infection
T6	Sixth thoracic spinal cord level
T10	Tenth thoracic spinal cord level
UTI	Urinary tract infection

