

Pregnancy and Spinal Cord Injury

An information booklet for women with SCI

Created in partnership with:

Vancouver Coastal Health's Sexual Health
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Rick Hansen Institute

Spinal Cord Injury BC (SCI BC)

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This booklet is available as a free download:
sexualhealth.sci-bc.ca/scipregnancy

Disclaimer: Please note that the information contained in this publication is for general information only. It is meant to be used only as a guide and should not replace consultation with a medical professional.

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Icons sourced from nounproject.com and licensed under Creative Commons CC BY 3.0. Modifications to original icons include: wheel added and body cropped (outside front cover); two bottle icons combined (Medications); mobile stars added (Equipment); "pain" lines added (Spasticity); wheel added, person feminized, body cropped (Emotional); "pain" lines and wheel added, body cropped (Labour); heart added to person (Support); doctor and baby removed (Delivery); "play" arrow removed (Resources).





Yes, you can do it!

Whether you are thinking about becoming pregnant or are currently pregnant, this is an exciting time! Women with SCI can gain a lot of knowledge about pregnancy using their available supports and resources: talking with their community care providers, viewing recommended online maternity care websites, talking to other

As a woman with a spinal cord injury, you are able to become pregnant and give birth to a healthy baby! There are however, some things to keep in mind along the journey to maintain health and wellness for you and your baby.

women with SCI who are parenting, chatting with friends and family or attending parenting sessions offered in the community.

However, finding information related specifically to SCI and pregnancy can be difficult. We have created this booklet to highlight a number of key topics for women with SCI and their families to consider during the perinatal period, defined as the time before conceiving (pre-conception), pregnancy, labour,

delivery and postpartum (the first few days and weeks after a baby is born).

In this booklet we address the most common concerns for women with SCI. It is important to stress that not everyone will experience ALL of these concerns, and you may have unique questions and specific health related concerns.

The topics covered in this guide are designed as a place to start the conversation with your health care providers as part of planning for your care.



Starting off

If possible, consult with your doctor early on in the planning stage of becoming pregnant. In general, it is important to have a family doctor who provides consistent care to you throughout your life milestones. Wherever you are in your perinatal

Most, but not all, women are fertile. SCI does not hinder your potential to become pregnant, go through pregnancy, deliver a healthy child and take an active role in parenting. The information and suggestions in this guide will help you prepare and plan for your perinatal journey.

journey, you need a referral to an obstetrician or maternal fetal medicine specialist to talk about planning for your unique health needs. Ideally this would occur prior to you becoming pregnant. It is important that you make connections between the care team managing your spinal cord injury and your maternal care practitioners. Your family doctor plays an important role in providing ongoing health care for both pregnancy and non-pregnancy related health issues. You may find it helpful to talk to other women with SCI who are mothers to gain peer support and encouragement. Speak with

members of your care team to explore ways to connect with other women with SCI who are mothers, contact a local SCI-related organization like SCI BC, and utilize the various resources listed at the end of this booklet.

Setting up your pregnancy care team

The following is a list of care providers you may want to consider as part of your **pregnancy care team**:

- **Primary Care provider** – family doctor or nurse practitioner
- **Physiatrist** – physical medicine and rehabilitation doctor
- **SCI rehab team** – occupational therapist, physiotherapist, registered nurse
- **Maternity Care provider** – obstetrician, midwife
- **Maternal Fetal Medicine team** – maternal fetal medicine doctor, advanced practice nurse



In smaller centres, the resources available for your team may be dependent upon the hospital or rehabilitation facility. To be proactive in your care, it will be important

It can be challenging to locate information that is specific to women with spinal cord injuries who are pregnant or considering pregnancy.

to work with available members of your care team to create a document (often called a **care plan**) that outlines any medical or practical issues that will need to be considered during your pregnancy, labour and delivery, and in the first few weeks after returning home with baby. Identify who in your care team will be responsible for follow up care immediately post

delivery and once discharged home. Have a discussion with these care providers to determine when these appointments should occur.

Getting pregnant

Your ability to get pregnant after injury is approximately the same as prior to injury. Most women with SCI do not require any special services or procedures to get pregnant. You may want to take some time (if your injury is recent) before becoming pregnant. Menstrual cycles usually resume about 2-8 months following SCI. If you are considering pregnancy, talk to your doctor so that you are aware of the potential risks that are associated with pregnancy, especially in the first year following injury.





Medications

Review the list of your medications with your doctor to determine their safety in pregnancy (and postpartum if you are breastfeeding).

It is important to **discuss the medications, supplements or natural remedies you take with your care team** prior to getting pregnant or, if this is not possible, as early in the pregnancy as you can, as some of these medications may affect the baby's growth and development. In consultation with your doctors, you may decide to decrease your dose, stop taking some of your medications, supplements or remedies, or make changes to alternate medications. As with all women, alcohol consumption and smoking should be stopped during pregnancy and breastfeeding.



Bladder Function

As with any pregnancy, the growing baby puts pressure on the bladder, which decreases how much urine your bladder can hold. You may have to make changes to how you manage your bladder.

For example, more frequent intermittent catheterization may be required. Talk to your care team about **ways to manage issues** such as urgency to urinate and the frequency of urination, risk of leakage, risk of urinary tract infections (often referred to as UTI's), and how to control new or worsening bladder spasms. It is important to note that pregnancy increases the risk of urinary tract infections for all women and if left untreated, a urinary tract infection can lead to premature labour. Have your urine checked often for signs of infection. In some cases, you may be given antibiotics to treat or prevent a urinary tract infection.

Discuss with the medical team a plan for resuming bladder and bowel care following delivery as vaginal birth may make these challenging due to swelling and bleeding in first few days after delivery.





Bowel Function

Many pregnant women experience constipation during pregnancy.

While the increasing size of uterus puts pressure on the bowel, there is also a **decrease in bowel motility** (the coordinated movement of the lower part of your digestive system that moves fecal contents along) as a result of increased progesterin (hormone) and iron supplementation. You may find it more difficult to be independent with your bowel routine due to weight gain and balance issues. Talk with your care team about the best options available to manage your individual bowel needs during pregnancy.



Autonomic Dysreflexia

If your SCI is above T6 and you have experienced autonomic dysreflexia (AD) as a result of your injury, there is an increased risk that AD may happen during your pregnancy and labour.

As a woman with SCI, you are aware of how to recognize your own symptoms and manage AD. The medications used to treat AD must be reviewed with your doctor to make sure they are safe for pregnancy. During labour and delivery, contractions of the uterus can cause AD. The signs of AD can also look the same as another pregnancy condition called pre-eclampsia (high blood pressure and loss of protein in the urine). Although they look very similar, pre-eclampsia and autonomic dysreflexia are very different conditions and your care team will know how to manage them. Your **blood pressure will be carefully monitored** when you are in labour to recognize and prevent any complications from AD: you may even require an epidural to help decrease your symptoms of AD. Even during the first few weeks immediately after your baby is born, you should continue to have your blood pressure checked by your care providers. When you go home from the hospital, make sure you have a clear support plan to help you manage if you get AD symptoms. It is important that you are aware of AD and its management so that you will know when to go to the emergency room if symptoms are worsening and/or not improving.

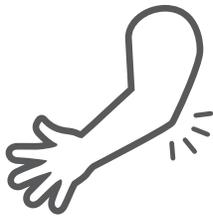




Deep Vein Thrombosis

Pregnant women in general are at increased risk for deep vein thrombosis (DVT).

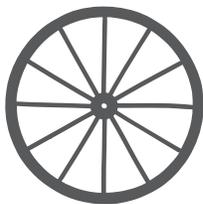
It is not clear whether or not pregnant women with SCI are at a higher risk for DVT than the general pregnant population. Talk with your medical care team about your individual health situation as well as **interventions that help to reduce the risk** (e.g. compression stockings, medications, passive range of motion exercises to encourage circulation in lower limbs).



Spasticity

As your body changes during pregnancy, you may notice an increase in your spasms.

Talk to your care team about the best way to manage spasms during pregnancy (e.g. **massage, change in body position**). Keep in mind that spasms can increase for reasons not related to your pregnancy (e.g. spasms may indicate of a urinary tract infection, or signal pain or pressure below your level of injury) so it will be important for you to notice any changes in the frequency or intensity of your spasms.



Mobility + Accessibility

Changes to your body during pregnancy will affect your mobility and accessibility needs. (e.g. the ability to transfer to different heights or reach to open doors, carry objects, or access to washroom facilities may be affected).

Having access to your care providers offices, perinatal classes, ultrasound facilities, or mom and baby support groups is important. **You may experience new access issues** such as needing a wheelchair accessible scale to monitor your weight. Throughout pregnancy, you may have to adjust your wheelchair



to accommodate changes in weight and centre of gravity. **Transfers may become more difficult** as your body grows and alters your centre of balance and/or if you experience an increase in spasms. Talk with your care team about your needs for positioning and mobility during your pregnancy and after you have given birth.

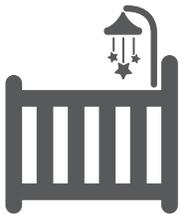


Skin Integrity

With pregnancy weight gain and increased fatigue, your skin becomes more at risk of breakdown, leading to pressure sores (also called pressure ulcers).

Frequent weight shifts with position changes can help prevent skin breakdown. It is important to do **regular skin checks** to monitor skin condition throughout your pregnancy and in the first few weeks after giving birth.

You may find it helpful to ask for the assistance of a caregiver or loved one or use a mirror to monitor for skin changes.



Equipment

Your equipment for everyday needs may change during pregnancy and for the first few weeks after you have delivered your baby (e.g. raised toilet seat, shower transfer bench, sliding board for transfers).

Discuss your equipment needs with your team. You can **explore options for renting or borrowing equipment** if it is only needed for a short time. If equipment is needed longer term, talk to your care team about **potential funding options**. Also consider the **equipment that you may need during your hospital stay**, such as an accessible bassinet and accessible bathroom equipment (e.g. shower chair, raised toilet seat, transfer board).



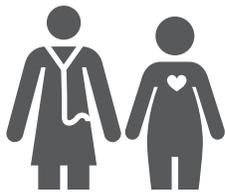


Planning for the Birth

Babies can be delivered either vaginally (naturally) or surgically by caesarean section (also known as “C-section”).

A vaginal birth is possible and even preferable; the decision for a C-section birth should only be for medical indications, as necessary. Your choice in the way your baby is delivered should be discussed with your maternal care provider prior to going into labour.

In your chosen birthing centre, explore the resources available to support you having a vaginal birth. Work with your care team in advance to [create an individualized care plan](#) to document your wishes and the required resources (e.g. an egg crate mattress on the labour bed can be very helpful to prevent pressure sores from forming).



Selecting a Labour Support Team

Planning to have a supportive team of health care providers such as a midwife and/or a doula, (a non-medical birth companion), friends and/or family ready to help during and after labour can be beneficial.

It’s not always easy to find health providers with experience in supporting mothers with SCI. Try asking other mothers with SCI or organizations that support people with SCI for names of health care providers they recommend. If you have already hired caregivers, [find out the birthing centre’s policies](#) about what role they can continue to provide during and after delivery and throughout your hospital stay.





Labour

Even if your sensation is altered below the level of SCI, you may experience signals elsewhere that you are going into labour.

Recognizing Signs

Women with SCI may not be aware of signs of labour (painful uterine contractions), but often experience symptoms such as **non-specific shoulder or back pain, increased spasticity, AD, or sinus pain with contractions when in labour**. You may be able to feel a tightening in the uterus when placing your hand on your abdomen. Women with SCI must have more frequent check-up appointments with their care provider as the due date gets closer.

During Labour

As a woman with a spinal cord injury, there are some additional things to consider during labour.

1. An intravenous line (IV) for fluids is often used for women in labour. You may want to consider asking your care provider to place the IV in your upper arm rather than in the lower forearm (as is typically done) so that it does not interfere with your ability to transfer or shift your position.
2. An epidural anesthetic is required for women with SCI above T6 to control for AD.
3. Consider the use of a foley catheter during labour to avoid the need for intermittent catheterization for bladder management.
4. Regular or continuous blood pressure monitoring is vital in recognizing the signs of AD during labour.
5. Frequent turns and repositioning are also important to reduce the risk of skin breakdown.





Once Baby Arrives

When planning for the first few days and weeks after baby arrives, there are many things to consider.

You may be exhausted recovering from the birth and may require more assistance than usual after labour. When you are in hospital for delivery and postpartum care, **think about who will help with other children and household tasks.**

Transfers may also be a bit tricky in those first few days postpartum while your body heals after delivery. You may want to think about how you will **safely and comfortably manage transfers** in the hours and first few days immediately after the baby's birth when parts of your body might be quite sore and swollen. You may want to explore with your care team any **equipment that might be helpful** during this time (ie, transfer board, shower transfer bench, commode chair, raised toilet seat, etc) and ask them to check your skin.

Once you are ready to return home, transportation and baby care needs have to be in place. These include:

1. **Transportation** (e.g. ease or difficulty of car transfers post delivery and specialized baby car seats that can rotate for you);
2. **Finding baby care items** that work for you (e.g. cribs, bassinets, change tables, slings, and baby carriers) and;
3. **Identifying what supports you may need** during the first few weeks as you adjust to parenthood. Many women find it helpful to talk with family and friends prior to baby's arrival about the things that would be helpful for them to do when baby arrives (e.g. helping with dishes, laundry, meals). Many women hire a postpartum doula during these first few weeks for emotional and practical support to preserve your energy (e.g. help with baby care, feeding, household tasks, first outings with baby, allow you to nap).

Other moms and parents with SCI can be great sources of information on tips and tricks to adjusting and adapting your home and routines for life with your newborn. Organizations like the Tetra Society can help make customized adaptations to baby items that allow you to be more independent as a parent.





Emotional Health

All new mothers should be aware of changes in their mental and emotional health following birth.

It is common for many new mothers to feel anxious, isolated, unsupported, or inadequate as they struggle to adjust to their lives with their newborn. For new mothers with SCI, mobility challenges and their dependence on the need for their own supports for daily living **can heighten these emotional health issues**. Support from family, social networks, other new parents with SCI, and your care team can help with your emotional adjustment.

However, some emotional health changes are more serious and will require professional help. This is true of **postpartum depression**.

Postpartum depression seems to be more common amongst women with SCI. The following are signs of postpartum depression.

- You are still feeling the “baby blues” two weeks after birth
- You aren’t feeling like “yourself”
- Negative thoughts and feelings are strong (sadness, anxiety, worry, guilt)
- You are having difficulty falling asleep, staying asleep or you are sleeping too much
- You are not hungry or food is not appealing
- You are feeling mad at your baby
- You are worrying about your baby too much or too little
- You are thinking about hurting yourself or your baby

If you find that you are experiencing these feelings – **do not be afraid to seek help!** With time these symptoms, for some women, will not go away on their own. Talk to your doctor, nurse, nurse practitioner or midwife about getting help. Treatment and counseling can help to relieve these feelings. You are not alone.





Breastfeeding

You may wish to consult with a physiatrist about whether breastfeeding is possible given your level of SCI. Sometimes women with injuries T6 and above are not able to breastfeed for physiological reasons.

Many women (regardless of having an SCI) find that breastfeeding can be challenging. **Consider meeting with a lactation consultant** prior to delivery to explore different techniques and positions to try out. After the birth of your baby, it is helpful to meet with a lactation consultant or other professional who has been trained to support breastfeeding (ie, nurse, doula, midwife), or to **connect with a local support group** such as a Le Leche League group. If you continue to have difficulties, you may want to ask to be referred to a medical clinic that specializes in breastfeeding. Other mothers with SCI can be good sources of information as well.

Above all, **don't be hard on yourself** if you are unable to breastfeed. Talk to your support team about options available to continue to encourage a positive feeding and bonding experience, (e.g. such as skin- to- skin contact, use of a supplemental feeding system, holding your baby in a position similar to breastfeeding when bottlefeeding).

At this time you should speak with your family doctor or physiatrist about resuming medications and your birth control options.





Resources

For more specific information on the topics discussed in this booklet, you may find the following resources useful:

YOU TUBE VIDEOS

[Raising children from a wheelchair CPA Alberta video](#)

https://www.youtube.com/watch?v=dWZI_wFwZnE

[Wheelchair stroller and adaptable crib video](#)

<https://www.youtube.com/watch?v=AsAX3WZnflg>

WEBSITES

[SCI Parenting](#)

A website based in Sweden discussing all aspects of the perinatal journey for women with SCI

www.sciparenting.com

[Through the Looking Glass](#)

Information on parenting with a disability (e.g. DVDs and a book on Parenting Techniques & Adaptations)

<http://www.lookingglass.org>

[Assistive Technology for Parents with Disabilities](#)

A downloadable handbook.

http://www.idahoat.org/Portals/0/Documents/parent_disabilities.pdf

[Parents with Disabilities Online](#)

On-line resource for parents with disabilities including information on adaptive parenting aids

http://www.disabledparents.net/?page_id=89

[The Wheelchair Mommy](#)

An on-line blog depicting one women's experiences of being a mother with an SCI

www.wheelchairmommy.com



ORGANIZATIONS

The Society of Obstetricians and Gynaecologists of Canada

General pregnancy information

<http://pregnancy.sogc.org>

Spinal Cord Injury BC

Peer support and information services

http://sci_bc.ca

Tetra Society of North America

<http://www.tetrasociety.org>

Sexual Health Rehabilitation Service

Vancouver Coastal Health, Vancouver, BC Canada

sexualhealth.sci-bc.ca

Maternal Fetal Medicine Clinic

BC Women's Hospital and Health Centre, Vancouver, BC Canada

<http://www.bcwomens.ca/Services/PregnancyBirthNewborns/clinics/MaternalFetalMedicine.htm>

BOOKS

Maternity Roles

By Heather Kuttai on the experience of being a mother with SCI

The Disabled Woman's Guide to Pregnancy and Birth

By Judith Rogers

