

Breastfeeding Following Spinal Cord Injury: Consumer Guide for Mothers

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The World Health Organization (WHO) recommends that infants be breastfed exclusively for the first 6 months of age. However, there are few resources available on the effects a spinal cord injury (SCI) can have for breastfeeding mothers. It is difficult to find information to address the unique challenges women with SCI experience when planning or trying to breastfeed. Our international team, including women with SCI, health care providers, and SCI researchers, aims to address the information gap through the creation of this consumer guide. The purpose of this consumer guide is to share the most common issues women with SCI experience during breastfeeding and provide information, practical suggestions, recommendations, and key resources in lay language. General information about breastfeeding is available on the internet, in books, or from friends and health care providers. We do not intend to repeat nor replace general breastfeeding information or medical advice. Breastfeeding for mothers with SCI is complex and requires a team of health care providers with complementary expertise. Such a team may include family physician, obstetrician, physiatrist, neurologist, occupational and physical therapist, lactation consultant, midwife, and psychologist. We hope this consumer guide can serve as a quick reference guide for mothers with SCI planning of trying to breastfeed. This guide will also be helpful to health care providers as an educational tool. **Key words:** breastfeeding, consumers, motherhood, spinal cord injury

Introduction and Purpose of This Guide

There are few resources available addressing the effects a spinal cord injury (SCI) can have on breastfeeding. It is difficult to find information about the unique challenges or concerns women with SCI experience when planning or trying to breastfeed.

The purpose of this consumer guide is to share with you the most common issues women with SCI experience during breastfeeding. This guide also provides information, practical suggestions, recommendations, and key resources.

This consumer guide was created using a Delphi process through a collaboration between mothers

with SCI and researchers and clinicians with relevant expertise. Our panel of experts was surveyed regarding the desired structure and content. We decided on a question-and-answer format using everyday language and ultimately arrived at this final version after several rounds of discussion.

Many of the questions and concerns women with SCI have shared with us are outlined in this guide. The information, recommendations, and resources are intended to help you to gather information, guide your breastfeeding planning, problem solve common challenges, or explore new ways of doing things as you find a feeding plan that is the right fit for you and your baby.

General information about breastfeeding is available on the internet, in books, or from your friends and health care providers. We do not intend to repeat nor replace general breastfeeding information or medical advice. Breastfeeding in women with SCI is complex and requires a team of health care providers with complementary expertise. Such a team can include family physician, obstetrician, physiatrist, neurologist, occupational therapist, physical therapist, lactation consultant, midwife, psychologist, peer counsellor, and so on.

We hope that this consumer guide, with its facts, tips, and resources specifically related to breastfeeding after SCI, will benefit mothers with lived experience.

Commonly Asked Questions with Recommendations

I. Breastfeeding Basics

1. Can I breastfeed?

Most, but not all, women with SCI can breastfeed. Just like women without SCI, you are encouraged to give breastfeeding a try. By trying, you can then see if and how it works for both you and for your baby. If breastfeeding does not work well for you, there are several safe and healthy options available to ensure both your needs and your baby's needs are met.

Recommendations

- You are encouraged to try to breastfeed and see how it goes for you and your baby.

- If you have challenges or questions about breastfeeding, talk to your health care providers who are familiar with SCI management and/or breastfeeding. You may wish to share a copy of this resource guide with your providers to facilitate discussion.

2. What are the benefits of breastfeeding?

Breastfeeding has many benefits for babies' physical, developmental, and emotional health regardless of whether the breastfeeding mother has SCI or not.^{1,2}

The benefits for your baby include:

- Providing the ideal nutrition (breast milk has the perfect amount of protein, carbohydrates, fat, vitamins, and minerals and is easy to digest).
- Providing antibodies to protect against illness while baby's immune system develops.
- Lowering the likelihood of obesity, diabetes, and other diseases developing in childhood.
- Lowering infant mortality.

The benefits for mothers include:

- Increasing bonding and relaxation.
- Reducing costs.
- Convenience afforded by milk from the breast.
- Lowering the risk of future breast and ovarian cancers.
- Decreasing the potential of cardiovascular disease and type 2 diabetes.

It is important for every woman to feel supported as she explores how best to balance her own unique needs and abilities with the known benefits and risks of the various ways to feed her child (breastfeeding, supplementing, and/or formula feeding).

3. What are the challenges during breastfeeding?

Everyone is different, and it is not possible to predict your ability to produce breast milk and breastfeed your baby. Some challenges during breastfeeding are similar between women with and without SCI. However, it is important to recognize

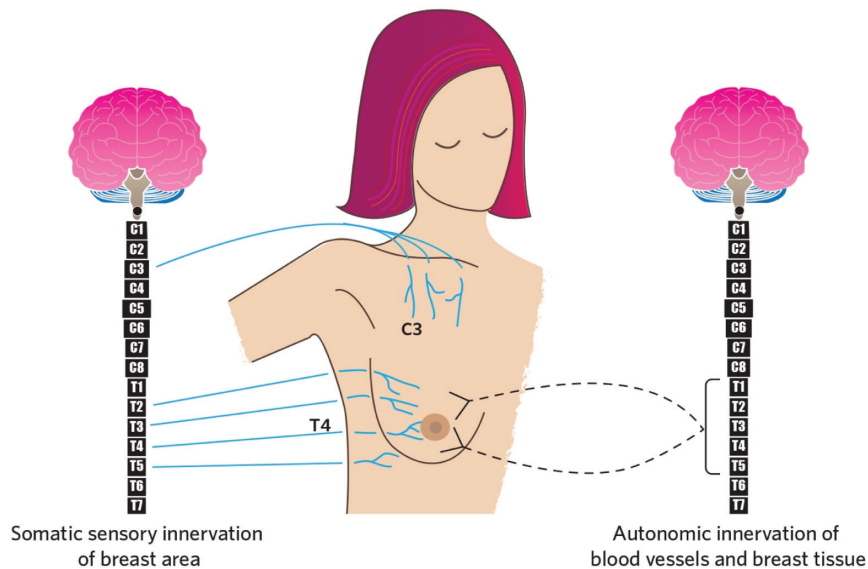


Figure 1. The somatic sensory (voluntary) and autonomic (involuntary) innervation (control) of the breast by the nervous systems. Black lines show the autonomic nerves (T1-T5 spinal cord levels) innervating breast tissues and blood vessels. Blue lines show the cervical (C) and thoracic (T) spinal nerves that convey sensory control of the breast and nipple areas. Milk production is a result of the coordinated functioning of the somatic and autonomic nervous systems.

that mothers with SCI face other concerns during breastfeeding related to the injury. These unique challenges can sometimes result in women with SCI feeling alone, lost, or as if they have failed.

Depending on the level of injury, challenges with breastfeeding following SCI may include:

- Limited milk production.
- Difficulties with positioning and latching the baby.
- Autonomic dysreflexia (AD), an abrupt and often dangerous spike in blood pressure.

Research shows that the higher and more complete the injury, the more likely breastfeeding difficulties will occur. Yet, with the right supports in place, you can define what successful breastfeeding means to you.

Recommendations

- Talk to your health care providers, including a lactation consultant and a physiatrist, for more information on how your SCI may be impeding breastfeeding.

II. Physical Aspects

4. *Will the level of my spinal cord injury affect my ability to breastfeed?*

The ability to breastfeed could be affected by the level and completeness of your injury.

First, if your injury is at or above the first thoracic (T1) spinal cord level, the movement and strength of your arms/hands could be affected, and you could have trouble with positioning and holding your child during breastfeeding. Typically, women with tetraplegia (cervical spinal cord injuries) experience these difficulties (see II. Physical Aspects, 7. *What specific positions and aids can I use to help me with breastfeeding?*).

Second, if your injury is at or above the fifth thoracic (T5) spinal cord level, this could result in decreased or loss of sensory control of area of the nipple/breast area and affect milk production. These levels of injuries could also result in decrease or loss of body responses that occur during breastfeeding that are important for milk production (physiological reflexes known as “let down reflex”) (see **Figure 1**).

Recommendation

- Discuss the potential impact of SCI on your ability to breastfeed with medical professionals (such as a physiatrist) and support team before planning a pregnancy or before delivery.

5. How will I be able to get my baby to latch effectively?

Like all mothers, women with SCI may experience common breastfeeding challenges, such as

- babies who have difficulty latching/feeding due to issues like prematurity, tongue tie, or jaundice and
- mothers with inverted nipples, infection (clogged ducts, mastitis), or an overabundance of milk.

There are also additional considerations specific to SCI that can make latching challenging, including sensory changes, motor effects, and fatigue, as outlined below.

Be aware that sensory changes in your body could affect your ability to breastfeed. If you have decreased nipple sensation, it may lead to altered let-down reflex and impaired milk production as well as limit the ability to recognize a poor latch that would normally cause pain. Visual signs during latching, feeding, and immediately after the feeding can help mothers identify a good latch. Use a mirror or have someone check the latch during the feeding and the breast for abrasions after feeding. During feeding, you should notice that your baby is changing the rate of sucking and appears to be swallowing. After feeding, you should check the condition of your nipples and whether your baby appears to be satisfied.

Be aware that strength and ability to move your upper extremities could impact your ability to breastfeed. Lack of mobility in your arms/hands, spasms, and impaired trunk strength or balance can affect how well the baby is positioned to access the breast, to get and keep a good latch that does not injure your nipples, and to reposition when needed. See II. Physical Aspects, 7. *What*

specific positions and aids can I use to help me with breastfeeding? for recommendations for positioning during breastfeeding.

Recommendations

- Pay attention to your baby's quality of latching and swallowing during breastfeeding, particularly if you have decreased sensation in your nipples and breast area.
- Examine your nipples (either on your own or ask a care provider to assist you) before and after breastfeeding to look for nipple distortion.
- Consult with your health care team if you are having a hard time positioning your baby to breastfeed. They may be able to assist or can refer you to a knowledgeable health care provider such as an occupational therapist or physiotherapist to help you explore assistive aids.

6. What should I do if I cannot produce enough milk?

Many mothers worry about low breastmilk supply and that their baby will not get enough milk. If you have low milk supply, there are a few different options you could consider. You may wish to supplement your baby with breast milk (your own or donated) or formula by bottle or by using supplementary nursing system. This system works by placing one end of a very thin flexible tube into a formula bottle, taping the tube to your breast, and slipping the other end of the tube into the baby's mouth once they have latched.

There are three options for breastmilk expression: hand expression, manual breast pump, or electric breast pump. In hand expression, the mother uses her hands to squeeze milk from the breast. A manual breast pump, also known as a hand pump, depends on manual suction to remove milk. Electric breast pumps generate suction using an electric or battery-powered energy source. There are a variety of electric pump options, including wearable pumps that fit inside the bra, single electric pumps, or double electric pumps. When considering the type of pump to purchase, level of hand function needs to be considered. Additionally, infants' needs will also influence the choice of suitable

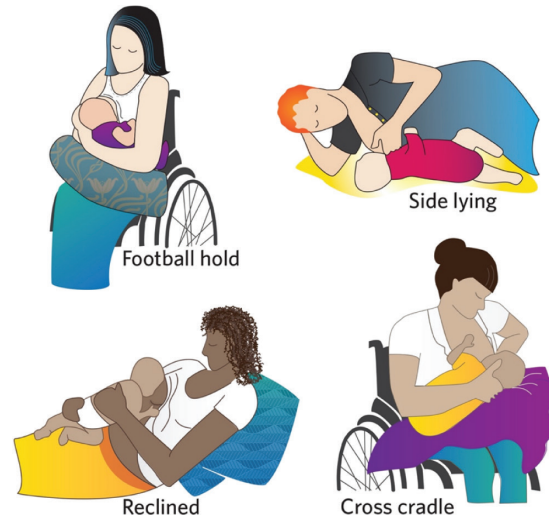


Figure 2. Breastfeeding positions that may be adapted for women with spinal cord injury.

pump; for example, a premature infant may not be ready for oral feeding at birth and thus might benefit from an electric pump capable of establishing and maintaining milk supply.

Recommendations

- Talk to your health care providers, including a lactation consultant and pediatrician, about the most safe and effective options for feeding your baby, as well as medications for you and your baby.
- If you have low milk supply, you can start by feeding your baby from your breast and then switching to a bottle after a specific amount of time or once the milk is gone from the breast.
- You can feed your baby at the breast with additional formula by using a supplementary nursing system.
- If you have enough hand function, you can express milk directly into your baby's mouth.
- A breast pump can be used to express the milk into a bottle that is then used to feed your baby.

7. What specific positions and aids can I use to help me with breastfeeding?

There are many things to consider in choosing a position for breastfeeding and skin-to-skin contact with baby. Your level of injury, fatigue, spasticity,

hand function, trunk stability, and time of day can influence if you choose to be in bed, in your wheelchair, or in a different chair to breastfeed. It may also be necessary to have someone else pick up your baby and position them for feeding. **Figure 2** shows the most used positions during breastfeeding by women with SCI.

Recommendations

- If you are having difficulties with positioning your baby during breastfeeding, ask for support from your health care providers (e.g., occupational therapists, physical therapists).
- *Wheelchair modifications* may be required to provide additional trunk support to increase stability while lifting and holding your baby. Adjusting the seat slope or backrest angle can change the center of gravity and improve stability. A backrest with deeper lateral trunk support or the use of a chest strap may also add stability. Changing the position of sideguards or widening the chair can allow for more room for the baby's body and legs when held in football or cross cradle positions. Please consult your occupational and physical therapists for assistance with these modifications.
- *Wedges* can provide support for sitting upright in a bed (providing support for the

back, belly, or the infant after birth) or can be used as leg support to reduce spasms and improve blood pressure.

- *Carriers* (harnesses, wraps, ring slings) can be used during breastfeeding and thereafter. They may be useful in positioning your baby when bottle-feeding or using a supplementary nursing system and can help to keep the baby upright after a feed to reduce spit-up/reflux.
- *Breastfeeding pillows* are available in a variety of shapes, weights, and stiffness (firm versus lighter and more flexible). Some mothers find that their own regular pillows work well if the breastfeeding pillows do not provide enough support.
- Adding a *long waist strap* to a breastfeeding pillow or infant carrier that also wraps around the wheelchair backrest can give added security and reduce the tendency for the pillow to slide forward or for you to lean forward while holding the weight of the infant in front.

8. What breast health issues should I be aware of?

Many women experience clogged milk ducts or even lactation mastitis (an inflammation of breast tissue that may or may not involve an infection but causes breast pain, swelling, warmth, fever, or chills) during their breastfeeding experience. Breast lumps are not uncommon.

Depending on the level of injury and hand function, women with SCI could be more likely to experience clogged ducts during breastfeeding. This happens when the breast is not fully emptied of milk at each feeding due to incomplete latching and suckling.

Limited hand function may also lead to poor milk expression and limit the mother's ability to perform self-lymphatic drainage and massage, which can contribute to the development of clogged ducts and mastitis.

Recommendations

- Wear a supportive bra (even at night) but avoid restrictive clothing.

- Change damp or soiled breast pads often.
- Shower daily and wash nipples with clear water only (no soap).
- Eat a healthy diet and stay well hydrated.
- Use gentle breast massage (if hand function is limited, use a massaging device or request assistance from partner or caregiver).
- Alternate use of hot and cold compresses if your breasts are engorged.
- If you have mastitis, check with your health care provider about how you can safely continue to breastfeed your baby.
- Be aware that pain from breastfeeding and mastitis could cause AD.

III. Special Considerations

9. Can I stay on my SCI medications and breastfeed at the same time?

Common medications used by women with SCI could go through the mother's bloodstream and into the milk, and many effects of medication on breastfeeding babies are not known. Speak with your health care team as each drug will need to be assessed of its risks compared to its benefits for you and for your baby. The goal should be to provide you with the necessary treatment while minimizing potential harmful effects on your baby.

There are excellent resources available to complement your consultation with your health care team, including the Drugs and Lactation Database (LactMed) and Hale's Medications & Mothers' Milk. The American Academy of Pediatrics and American College of Obstetricians and Gynecologists' best practices for breastfeeding³ while taking medications from have been summarized below:

- Ask your doctor about the possibility of transitioning to a safer drug or delaying the therapy.
- When possible, take medications right after a feeding session to allow for the longest possible period for drugs to exit your bloodstream.

- Inquire about any expected side effects and monitor your baby for these symptoms.

Recommendation

- Consult your health care team for advice about what medications to use, adjust, or discontinue while breastfeeding.

10. *Am I at risk for autonomic dysreflexia during breastfeeding?*

Autonomic dysreflexia (AD), defined as uncontrolled and potentially life-threatening spikes in systolic blood pressure by more than 20 mm Hg, may result in an increase of systolic blood pressure as high as 300 mm Hg. It is common for people with SCI at or above the sixth thoracic spinal cord segment (T6) to experience episodes of AD that can be caused by painful or nonpainful stimuli below the injury level. Episodes of AD have been documented in several studies of breastfeeding by women with higher level injuries. In women with SCI at or above the fourth thoracic segment (T4, level of sensory innervation of nipples), episodes of AD could be specifically triggered by stimuli from the nipples/breast area during breastfeeding. You should be aware that an episode of AD could be accompanied by severe headaches, sweating, and heart palpitations, or you could experience AD without any symptoms at all.

Breastfeeding-related AD may be caused by breastfeeding itself as well as by mastitis, nipple fissures, or other painful processes originating from the breast. Episodes of AD caused by breastfeeding may be much more common than we know. Recent research shows that one quarter of women with SCI experience AD while breastfeeding, and this number is higher in women with high level SCI (almost 40%).⁴

Frequent and uncontrolled episodes of AD could result not only in discomfort but also in significant negative health consequences, including damage to blood vessels and heart, stroke, seizures, and even death.⁵ It is vital to prevent and manage AD in a timely manner. Unfortunately, this topic is not commonly discussed in postpartum care, but it is vital to recognize and address.

Recommendations

- Be sure to discuss with your medical practitioner (e.g., physiatrist, family physician, or nurse) your blood pressure management and potential for development of AD.
- Be aware that women with SCI at or above T6 are at higher risk for the development of AD triggered by breastfeeding, clogged ducts, or mastitis.
- If you experience symptoms of AD, you should stop breastfeeding and measure your blood pressure if you can. Be sure that you are in seated position with your legs lowered. Wait until symptoms subside and your blood pressure goes down close to normal before you resume breastfeeding.
- Be aware that prolonged seating while breastfeeding may cause a decrease in your blood pressure (orthostatic hypotension) that could result in light-headedness and dizziness. If this occurs, elevate your legs or change your position to horizontal.
- Have a wallet information card on AD in case of admission to an emergency room.

IV. Emotional Health

11. *Will I have difficulty bonding with my baby if I have breastfeeding problems?*

Bonding, or what is often called “attachment” or the “caring connection” between a child and parent, is an important part of a child’s physical and emotional development.

Some parents report immediately feeling a strong connection with their child during pregnancy or soon after the birth. Other parents report they did not feel an instant connection. Both feelings are okay and normal.

Bonding and attachment can sometimes happen right away or can sometimes take weeks or months of getting to know and understand your baby to find what works best for you and your child and each of your unique needs.

Breastfeeding is not the only way to nurture or bond with your child. There are many other important ways to build connection and attachment between you and your baby.

Recommendations

- Find times to hold your baby against your bare skin. There are many positive benefits including body temperature regulation, breathing and heart rate regulation, calming effects, and improved sleep.
- Cuddle with your child. Ensure you have the chance to hold, rock, or carry your child during times that are not only related to feeding, bathing, diaper changes, or consoling. Those quiet moments can be important moments of connection and affection.
- Respond to your baby when they cry. This may be by gently touching their skin, picking them up, or using your voice. Let your baby know you are nearby and aware of their needs.
- Talk to your baby throughout the day. While this might feel awkward at first, try telling stories, describing people and the world around them, talking about what you are doing, or singing to your child.
- Look into your newborn's eyes while you feed or care for them. This helps your newborn to connect your face with your sounds and actions.
- Find ways to soothe yourself as well as your child. Take a few deep breaths. Listen to music you enjoy. Visit with friends you feel comfortable with. Look at a picture of a place where you like to spend time. Babies pick up on adults' feelings of tension and anxiety but also soak up their feelings of calm and comfort.

12. Am I more at risk for postpartum depression after delivery of my child?

The first few weeks after birth are exciting and challenging. It is a time of big changes as you bring your infant home, get to know them, and learn how to feed, bathe, and carry them. You also need to adjust to disrupted sleep patterns, manage your physical recovery after the birth, and try to find

time for your own daily living and self-care needs (e.g., eating, dressing, toileting, and bathing). For some mothers with SCI, your requirements for care may conflict with or delay the feeding times of your baby. Breastfeeding when you have an SCI can sometimes make some, or all, of these activities feel more challenging.

You may feel joy and excitement, but you may also feel sad, worried, or just be overwhelmed. This is understandable in the first few weeks after birth for any mother. This roller coaster of emotions is sometimes called “baby blues” and typically lasts a few days or up to a week or two. However, if the difficult feelings last longer and begin to impact your ability to participate in day-to-day activities, this can be a sign of what is called postpartum depression.

Postpartum depression can involve feeling sad, down, or crying easily, but it can also sometimes involve feeling worried, agitated, anxious, or an overwhelming fear that something awful is about to happen.

Women with SCI are at higher risk for postpartum depression and anxiety due to several factors including:

- Mental health concerns prior to pregnancy,
- The stress of coping with multiple physical challenges during pregnancy and/or after the birth,
- Worry about other peoples' opinions or judgments,
- Struggling with pre-existing fatigue related to SCI and the extra energy required to complete routine tasks as well as new onset fatigue due to baby caregiving needs,
- Limited access to knowledgeable caregivers or peers who understand the unique joys and challenges of parenting with a SCI, or
- Other factors that we do not yet know or understand.

Whatever you are feeling, you are not alone. You are important and valued. Help is available. Talk to your partner, loved ones, or health care providers about your feelings and worries. For instance, you can create a feeding schedule with built-in support from your partner, family, and care aide. If needed,

immediate help is available 24/7 from local crisis phone lines, urgent care centers, or emergency departments. With support, many women soon begin to feel their mood improve, their anxiety lessen, feel more attached to their baby, and begin to experience many more positive moments of parenting as they learn tools to help cope with the hard times.

Recommendations

- Learn about the signs, symptoms, and resources related to postpartum depression and anxiety so you, your partner, your family, and your care aides will recognize when extra assistance may be necessary.
- Talk to your health care providers and seek out information from trusted websites online or connect with local community groups that support new parents.
- Share this information with your partner, a friend or a family member, or a health care provider during your pregnancy or after baby has arrived. Sometimes we need a bit of help to reach out for the services we need when we are feeling sad or anxious.
- Watch your mood during pregnancy and after birth and notice any changes in feelings of sadness or worry. Are these feelings improving or getting worse? Are they lasting longer than they did in the past?
- Know that feelings of sadness or anxiety happen to lots of people. You are not a failure, and you are not alone.
- Help is available 24/7. Accessing help can relieve pressure and often make a big difference in how you are feeling.

13. Where can I find additional support and information?

There are plenty of books on pregnancy, birth, and all the challenges with motherhood, but there is much less information for pregnant women and new mothers that have an SCI. Just like experiencing and learning about changes to your body during pregnancy, it is important to educate and advocate for yourself about being a mother and breastfeeding with an SCI.

Recommendations

- Look to your health care team. Your health care team involved in your pregnancy and birth is your primary trusted resource. Physiatrists have the medical knowledge to address concerns related to your SCI. Lactation consultants, midwives, and staff of public health agencies have knowledge about pregnancy, birth, and breastfeeding. These professionals, working together with you, can address your specific concerns.
- Look online for resources. If you don't have services locally, look for reputable and accredited sources in addition to information provided in this guide. Check your local or national spinal cord injury organizations. There are many dedicated websites in the medical community. Do an online internet search with some key words like "mom SCI and breastfeeding." Online videos, articles, and peers' stories provide opportunities for learning and making connections among a growing population of moms with SCI all around the world.
- Connect with other moms. Peer support is important for all new moms, including moms with SCI. Social media platforms like Facebook have many groups you could join and are a popular place to share questions and concerns and learn about equipment or adaptations ideas. Reach out to other moms in your community or online for advice, support, and social activities, especially outdoor activities allowing you to connect with nature.
- Stay connected. While there is no way to fully prevent postpartum depression or anxiety, it can be helpful to know the signs to look for and good habits to adopt. Turning to your support system, whether family, friends, or other trusted individuals in your community, can make a big difference to your mood and overall well-being.

Conflicts of Interest

The authors have no conflicts of interest to disclose.

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APPENDIX

Additional Information and Resources

Please see the resources listed by section.

II. Physical Aspects

5. How will I be able to get my baby to latch effectively?

City of Toronto, Toronto Public Health Division (TPH) and the Toronto East Health Network, Baby-Friendly Initiative (BFI) Strategy for Ontario. *Breastfeeding Protocol: Positioning and Latching*. January 2019. https://breastfeedingresourcesontario.ca/sites/default/files/pdf/Res_Strategy_Positioning_Latching.pdf

6. What should I do if I cannot produce enough milk?

Sikana Health Video. *How to Use a Supplemental Nursing System*. <https://www.youtube.com/watch?v=gRCitroQDvk>

7. What specific positions and aids can I use to help me with breastfeeding?

SCIRE. *Breastfeeding After Spinal Cord Injury: Assistive Aids* [video]. <https://www.youtube.com/watch?v=CxZMT5ODYQo&list=UUqfek1jG8erqZqieDbKvEVg&index=4>

8. What breast health issues should I be aware of?

Penn Medicine. *Breastfeeding Care Instructions* [article on general breast health]. <https://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/obstetrics/breastfeeding-services/care-guides/breastfeeding-basics>

Cleveland Clinic. *Mastitis* [article on care for mastitis]. <https://my.clevelandclinic.org/health/diseases/15613-mastitis#:~:text=Mastitis%20sometimes%20goes%20away%20without,flowing%20through%20the%20milk%20ducts>

III. Special Considerations

9. Can I stay on my SCI medications and breastfeed at the same time?

Hale's Medications & Mothers' Milk: <https://www.springerpub.com/hale-s-medications-mothers-milk-2023-9780826160638.html>

LactMed®, a database containing information on drugs and other chemicals to which breastfeeding mothers may be exposed: <https://www.ncbi.nlm.nih.gov/books/NBK501922/>

10. *Am I at risk for autonomic dysreflexia during breastfeeding?*

ABC of Autonomic Dysreflexia in Spinal Cord Injury: <https://www.abcofad.ca/>

Spinal Cord Injury Model System. *Autonomic Dysreflexia* [fact sheet]. November 2015. https://msktc.org/lib/docs/Factsheets/SCI_AutonomicDysreflexia.pdf

Paralyzed Veterans of America. *Autonomic Dysreflexia: What You Should Know. A Consumer Guide for People with Spinal Cord Injury*. June 2022. <https://pva.org/wp-content/uploads/2022/05/Autonomic-Dysreflexia-Consumer-Guide-2022.pdf>

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