

# Women's Health

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## Introduction

Women and girls with Spina Bifida have specific needs and concerns, especially in the context of sexuality, pregnancy, and childbirth. Every woman's and girl's body undergoes multiple changes throughout her lifetime, and these changes are further impacted by Spina Bifida.

More information is still needed regarding sexual response in women with Spina Bifida. Many factors may affect a woman's ability to position herself during sexual activity, including level of mobility, history of osteoporosis and fracture risk, and respiratory function.<sup>1</sup> Innervation also impacts the body's physiologic response to stimulation including vaginal engorgement, lubrication and the ability to achieve orgasm.

Women with Spina Bifida may have unique health concerns regarding their reproductive health, such as structural anomalies of the reproductive tract (such as a bicornuate uterus which may be found on exam or ultrasound). Changes to the hips and spine may require special attention to positioning during pelvic examinations and birth.<sup>1</sup> Many women with physical disabilities, including those with Spina Bifida, choose to become pregnant,<sup>2-3</sup> and with pregnancy come specific concerns, such as preterm birth and changes in a woman's bowel, bladder and mobility. Understanding how pregnancy will affect a woman with Spina Bifida, and how her current state of health and quality of life might be affected by pregnancy is critical to her ongoing health. Menopause can cause vasomotor symptoms and changes in vaginal and bladder health, and women may benefit from both lifestyle and medical management.<sup>4</sup>

This guideline aims to address many of the main health concerns specific to women with Spina Bifida.

## Outcomes

### Primary

1. Provide accurate information to women with Spina Bifida about the impact of Spina Bifida on pregnancy and the impact of pregnancy on women with Spina Bifida.

### Secondary

1. Help women with Spina Bifida maximize sexual functioning.

### Tertiary

1. Understand menopause management options for women with Spina Bifida.

## Women's Health Guidelines begin at age 6-12 years 11 months

### 6-12 years 11 months

#### Clinical Question

1. When do pubertal changes happen to girls with Spina Bifida?

#### Guidelines

1. Puberty occurs earlier in girls with Spina Bifida than in the general population. It is recommended that, along with Tanner staging, care providers discuss the possibility

- of early puberty with girls and their families and create an atmosphere of open communication.<sup>1</sup> (Endocrine: Puberty and Precocious Puberty Guidelines, Sexual Health and Education Guidelines)
2. Offer human papillomavirus (HPV) vaccination per Centers for Disease Control and Prevention and American Academy of Pediatrics guidelines, if appropriate.<sup>5-6</sup>

## **13-17 years 11 months**

### **Clinical Questions**

1. How can pelvic organ prolapse be managed?
2. What are the sexual education needs of girls with Spina Bifida?
3. What information and screening do girls need regarding contraception and sexually transmitted infections?

### **Guideline**

1. Manage pelvic organ prolapse, which can occur at any stage of life in women with Spina Bifida, in consultation with an urogynecologist. Take into account the possibility of decreased pelvic sensation.<sup>7</sup>
2. Provide guidance on reproduction, sexual health and education. (Sexual Health and Education Guidelines)
3. Contraception options should be made available and discussed to in a non-judgmental manner, taking into account health concerns such as decreased mobility, risk of decreased bone mineral density, latex allergy and use of antiepileptic medications and genetic risk factors.<sup>8,9</sup> (clinical consensus) Consider consulting a gynecologist in a complex scenario.
4. Offer HPV vaccination per Centers for Disease Control and Prevention and American Academy of Pediatrics guidelines, if appropriate.<sup>5-6</sup>

## **18+ years**

### **Clinical Questions**

1. How can we manage pelvic organ prolapse in adults with Spina Bifida?
2. What gynecological care should women with Spina Bifida have?
3. How can we maximize the physical sexual functioning of women with Spina Bifida, including orgasm and lubrication?
4. What is the impact of pregnancy on the global physiology of a woman with Spina Bifida?

### **Guidelines**

1. Manage pelvic organ prolapse, which can occur at any stage of life in women with Spina Bifida, in consultation with an urogynecologist. Take into account the possibility of decreased pelvic sensation.<sup>7</sup>
2. Encourage women with Spina Bifida to have routine gynecological care, including Pap smears and mammograms.<sup>10-11</sup>
3. Provide guidance on sexual health, education and birth control. (Sexual Health and Education Guidelines) Contraception options should be made available and discussed in a non-judgmental manner, taking into account health concerns such as decreased mobility, risk of decreased bone mineral density, latex allergy and use of antiepileptic medications and genetic risk factors.<sup>8,10</sup> (clinical consensus) Consider consulting a gynecologist in a complex scenario.
4. Raise awareness of availability of screening and treatment for sexually transmitted infections, and offered Pap smears as per guidelines.<sup>10</sup>
5. Provide gynecology exam rooms and tables that are accessible for women with physical disabilities. (clinical consensus)

6. Clinicians should initiate a discussion of sexual function with women with Spina Bifida in a sensitive manner to facilitate problem problem-solving and acknowledge common concerns such as inability to orgasm, prolonged time to achieve an orgasm, and decreased lubrication. In some cases, an experienced sexologist may be helpful.<sup>12</sup>
7. Encourage women with decreased pelvic sensation to explore other parts of the body with themselves or a partner, especially the lips, nipples, arms, and earlobes, or other areas of the skin, as they may find them to be more sensitive.<sup>13</sup>
8. Inform women that they can use commercially available sexual lubricants to improve lubrication.<sup>13</sup>
9. Women with urinary incontinence should be encouraged to catheterize or void before having sex to prevent incontinence during sex.<sup>13</sup>
10. Inform women that their choice of sexual positions may need to take into account their level of mobility, osteoporosis and fracture risk, and respiratory function.<sup>1</sup>
11. Motivate women with Spina Bifida to communicate with their sexual partners about what they enjoy and do not enjoy during sex.<sup>13</sup>
12. Recommend preconception consultation with an obstetrician who specializes in high-risk pregnancies. Depending on the woman's medical history, she may also benefit from preconception consultation with her neurosurgeon, urologist, physiatrists, and other health care providers to discuss the potential impact of pregnancy on health. (clinical consensus) (Prenatal Counseling Guidelines)
13. Recommend that women with Spina Bifida, who are at increased risk of having a baby with a neural tube defect, decrease their risk by taking a daily oral supplement of 4mg of folic acid starting at least 1 month but preferably 3 months prior to conception and continuing until 12 weeks of gestational age.<sup>14,15</sup> (Prenatal Counseling Guidelines)

## **Targeted Guidelines: Pregnancy**

### **General Considerations**

#### **Clinical Question**

1. What is the impact of Spina Bifida on pregnancy?

#### **Guidelines**

1. Discuss the increased risk of preterm birth and review the signs and symptoms of preterm birth in the context of the woman's sensory abilities.<sup>16</sup>
2. Inform women that maternal Spina Bifida increases a woman's chance of having a baby with Spina Bifida. (Prenatal Counseling Guidelines)

### **Musculoskeletal and Respiratory Considerations during Pregnancy**

#### **Clinical Questions**

1. How should respiratory function be monitored during pregnancy?
2. How should changes in mobility during pregnancy be managed?

#### **Guidelines**

1. Conduct pulmonary function testing at least once during pregnancy in the case of kyphoscoliosis. This is because dyspnea can occur during pregnancy when there is an associated kyphoscoliosis deformity. (clinical consensus)
2. Ask about symptoms of shortness of breath at each antenatal visit, and undertake pulmonary function testing or assess for pulmonary embolism as indicated.<sup>17,19</sup>

3. Consider temporary wheelchair use in women and girls who use braces and crutches to ambulate, to reduce the risk of falls and subsequently trauma to maternal joints and the fetus.<sup>18</sup>
4. Follow for back and leg pain and consider temporary wheelchair use (clinical consensus), modified bedrest, and massage and physical therapy if back and leg pain is severe.<sup>20</sup>
5. Consider referral to orthopaedics and physical medicine and rehabilitation as needed when there are significant or concerning changes in mobility. (clinical consensus)
6. Consider referral to occupational therapy and physical therapy early in pregnancy to discuss the impact of pregnancy on self-management ability as well as to discuss plans for after-delivery care and care of her baby.<sup>21-22</sup> (Self-Management and Independence Guidelines)

## **Bowel Care Considerations during Pregnancy**

### **Clinical Questions**

1. How should bowel concerns be managed during pregnancy?

### **Guidelines**

1. Discuss bowel care early in the pregnancy, as pregnancy can worsen constipation. A diet high in fibre, increased fluid intake and exercise can alleviate constipation, however are not always sufficient. Bulk-forming agents such as psyllium, stool softeners such as docusate sodium, lubricant laxatives, osmotic laxatives and stimulant laxatives are considered safe in pregnancy. However, osmotic and stimulant laxatives may cause significant abdominal cramping and bloating and therefore should not be used for a prolonged period of time.<sup>23</sup>
2. Consider having a consultation with a gastroenterologist or expert in neurogenic bowel management to maximize the methods to alleviate constipation. (clinical consensus)
3. Manage a suspected bowel obstruction with a team consisting of a general surgeon, neurosurgeon, and high-risk obstetrician. (clinical consensus)

## **Shunt Management Considerations during Pregnancy**

### **Clinical Questions**

1. How can shunt complications be assessed during pregnancy and how should they be managed?

### **Guidelines**

1. Review signs of increased pressure, headache, nausea, and vomiting at each prenatal visit because the enlarging uterus can cause a shunt malfunction by increasing intra-abdominal pressure.<sup>24</sup>
2. Manage signs of shunt malfunction with a team consisting of a neurosurgeon, obstetrician and anesthesiologist. Other specialties may be needed depending on the clinical scenario.<sup>24</sup>
3. Conduct a thorough workup for both preeclampsia and shunt obstruction if a pregnant woman with a shunt has nausea, vomiting, headache, or neurological symptoms. A preeclampsia workup consists of assessing for the following: fetal well-being; blood pressure; proteinuria; and blood work to test for elevated aspartate aminotransferase (AST), and alanine transaminase (ALT), and thrombocytopenia.<sup>24,25</sup>

## **Seizure Considerations during Pregnancy**

### **Clinical Question**

1. How should seizure risk be managed during pregnancy?

### **Guideline**

1. Optimize medical management of seizures prior to conception. Women who have a history of seizures have a higher risk of seizure during pregnancy and labor. If possible, avoid anticonvulsant medications that have a greater risk of teratogenicity while still providing good control.<sup>1</sup>

## **Bladder and Renal Function Considerations during Pregnancy**

### **Clinical Question**

1. What considerations should be made for bladder and kidney health during pregnancy?

### **Guidelines**

1. Perform regular urinalysis and urine culture tests throughout the pregnancy and treat infections promptly, as urinary tract infections are common during pregnancy in mothers with Spina Bifida.<sup>19,26-27</sup>
2. Make a baseline renal assessment, ideally prior to pregnancy or early in the pregnancy, in order to make appropriate referrals to nephrology care.<sup>28</sup>
3. Coordinate with a nephrologist to manage women with Spina Bifida who already have evidence of renal disease and a risk of decreased renal function in pregnancy.<sup>28-29</sup>
4. Perform intensified maternal and fetal monitoring with women who have renal disease in pregnancy and are at increased risk of preeclampsia and intrauterine growth restriction.<sup>25,27</sup>
5. Ask women at each visit about their ability to catheterize, and refer them to a urologist if there are concerns because urostomies can develop poor conduit drainage as the uterus grows.<sup>27,30</sup>
6. Urgently consult with urology specialists if women with continent urinary diversions develop increased incontinence or difficulties in intermittent self-catheterization.<sup>30</sup>

## **Targeted Considerations: Childbirth**

### **General Considerations during Childbirth**

#### **Clinical Question**

1. What are considerations for birth for a woman with Spina Bifida?

#### **Guidelines**

1. Consult a high-risk obstetrician when planning the mode of delivery. Although vaginal births are possible for women with Spina Bifida, severe spinal and pelvic skeletal deformities may prevent vaginal birth.<sup>17</sup>
2. Consider facilitating vaginal deliveries in women with ventriculoperitoneal (VP) shunts by means of a shortened pushing stage, possibly aided by a vacuum or forceps to decrease elevation of intracranial pressure.<sup>31</sup>
3. Teach women who may be unaware of labor contractions to palpate for hardening of the belly and observe for rupture of membranes, and watch for signs of autonomic dysreflexia.<sup>19,32</sup>
4. Watch for autonomic dysreflexia triggered by labor among women who have a lesion above T6. Autonomic dysreflexia can be life-threatening and women experiencing any signs or symptoms should seek emergency care and transportation to the hospital. As well, there is significant clinical overlap between autonomic dysreflexia and preeclampsia, and therefore the woman should be evaluated for both.<sup>19,32</sup>

5. Make the decision between a planned caesarean birth (with available urology back-up if needed) versus a planned trial of a vaginal birth (with the associated risks of having an emergency caesarean birth) in conjunction with a team consisting of an anesthesiologist, urologist, and obstetrician, and acknowledge the woman's goals and preferences. Keep in mind that a caesarean birth in a woman with previous lower urinary tract surgery may be complex. Intestinal and omental adhesions to the lower uterine segment may necessitate a classic upper segment section.<sup>30</sup>
6. Recommend a caesarean birth to protect continence for women with vesical neck reconstruction or artificial sphincter placement.<sup>27</sup>
7. Take into account that pregnancy itself can exacerbate an existing pelvic organ prolapse and that a vaginal birth will likely exacerbate it. Consider the impact of a worsening pelvic organ prolapse, and the possible need for subsequent surgery, in consultation with an obstetrician and urogynecologist, and taking into account the woman's preferences. The plan for the mode of birth should take into account the impact of this worsening and the possible need for subsequent surgery in consultation with an obstetrician and urogynecologist, and acknowledge the woman's preferences.<sup>27</sup>
8. Consider that Spina Bifida can be associated with congenital renal malformations such as horseshoe kidney and pelvic kidney.<sup>33</sup> If a caesarean birth is required, the surgeon should be aware of unique renal anatomy prior to conducting the surgery if needed.
9. Ensure that a consultant urologist be available for the caesarean birth in women who have had a previous lower urinary tract surgery.<sup>34</sup>
10. Keep in mind that Spina Bifida is not a contraindication to epidural anesthesia. As such, ensure that each woman has an anesthesia consultation prior to delivery to discuss the risks and benefits of regional versus general anesthesia.<sup>36-37</sup>

## **Targeted Considerations: Breastfeeding**

### **General Considerations for Breastfeeding**

#### **Clinical Question**

1. Is breastfeeding impacted by Spina Bifida? If so, how?

#### **Guidelines**

1. Encourage mothers who wish to breastfeed to do so and provide them with support from a lactation consultant. Keep in mind that there is no literature specifically about breastfeeding in the context of Spina Bifida. (clinical consensus) (Nutrition, Metabolic Syndrome, and Obesity Guidelines)
2. Be aware that while anti-epileptic medications are for the most part considered compatible with breastfeeding, some require close monitoring of the baby for side effects and a reduction in the baby's exposure. Consider informing mothers of any possible side effects associated with an anti-epileptic medication they are taking while breastfeeding.<sup>38</sup>

## **Targeted Considerations: Menopause**

### **General Considerations during Menopause**

#### **Clinical Questions**

1. How should vasomotor symptoms of menopause be managed by women with Spina Bifida?
2. How should the urogenital changes of menopause be managed by women with Spina Bifida?
3. How should women be screened for breast and gynecological cancers?

### **Guidelines**

1. Inform women that vasomotor symptoms such as hot flashes can sometimes be managed by lifestyle changes such as avoiding alcohol, cigarette smoking and warm drinks, as well as maintaining a normal body mass index.<sup>4</sup>
2. Take into account that medical management of vasomotor symptoms includes both hormonal and non-hormonal prescription medication. Decisions on which medication to take should be made in conjunction with a physician experienced in managing menopausal symptoms, and take into consideration the severity of the woman's symptoms, bone mineral density, risk for blood clots, and behavioral or emotional symptoms such as depression.<sup>4</sup>
3. Inform women with vaginal dryness that they may benefit from topical vaginal lubricants.<sup>4</sup>
4. Consider treating vaginal atrophy with vaginal estrogen by a physician experienced in managing the symptoms of menopause. This may also help with urinary urge incontinence and may prevent some urinary tract infections.<sup>4</sup>
5. Women should be made aware of their breast anatomy, and should be encouraged to bring any changes to the attention of their physician.<sup>38</sup>
6. Women should participate in breast cancer screening programs, which for many women will begin at age 45. This may be initiated sooner if there is a family history or other risk factors for breast cancers.<sup>39</sup>
7. Women should continue to participate in cervical cancer screening programs in accordance with local guidelines.<sup>10</sup>
8. Women should be made aware that abnormal vaginal perimenopausal bleeding and post-menopausal bleeding can be a sign of endometrial cancer. Strongly encourage women to tell their physician if they experience abnormal perimenopausal bleeding or any spotting or bleeding after menopause.<sup>40</sup>

## **Targeted Considerations: Deep Vein Thrombosis**

### **General Considerations for Deep Vein Thrombosis**

#### **Clinical Question**

1. When do girls and women with Spina Bifida need thromboprophylaxis?

#### **Guideline**

1. Consider thromboprophylaxis on a case-by-case basis for girls and women with limited mobility and those who use wheelchairs. Girls and women with decreased mobility may have an increased risk of deep vein thrombosis and pulmonary embolism in pregnancy. Girls and women with thrombophilia; BMI>30; those who smoke; those with pelvic girdle pain that restricts mobility; those undergoing caesarean section or prolonged labor; those with preeclampsia; and those with a preterm birth are at further risk. Consider consultation with hematology to assist with risk assessment and thromboprophylaxis duration.<sup>41</sup>

## **Research Gaps**

1. There is no information available on the effect of pregnancy on continence.
2. There is no literature specifically on breastfeeding in the context of Spina Bifida.
3. More research is required to understand the incidence and cause of preterm birth in women with Spina Bifida.
4. More research is required to understand the incidence of gestational diabetes, preeclampsia, malpresentation and postpartum complications in women with Spina Bifida.
5. There is limited information on maximizing the physical sexual functioning of women with Spina Bifida.
6. There is limited information on the management of menopause symptoms specifically for women with Spina Bifida.

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