

## Spina Bifida Guideline

# Women's health guidelines for the care of people with spina bifida

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**Abstract.** Women and girls with spina bifida have specific health care concerns. It is essential that they, and their health care providers have access to information to help them make healthy choices throughout their lifespan. This article aims to address key aspects of health pertinent to girls and women with spina bifida and outlines the SB Women's Health Guidelines for the Care of People with Spina Bifida. Further research into this area is needed.

Keywords: Myelomeningocele, spina bifida, pregnancy, women's health, birth, contraception, menopause, neural tube defects

## 1. Introduction

Women and girls with spina bifida have specific needs and concerns, especially in the context of puberty, sexuality, pregnancy and childbirth, and menopause. Throughout their lifetime, every woman and girl's body undergoes multiple changes which are further impacted by spina bifida.

Girls with spina bifida may go through puberty early, and will need information and support during this process. Women with spina bifida may have unique health concerns regarding their reproductive health, such as structural anomalies of the reproductive tract (for example, a bicornuate uterus may be found on exam or ultrasound). Changes to the hips and spine may require special attention to positioning during pelvic examinations and birth. 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, res-

piratory function, history of osteoporosis and fracture risk [1].

Many with physical disabilities, including those with spina bifida, choose to become pregnant [2,3]. However this comes with specific concerns, such as preterm birth and changes in a woman's bowel, bladder and mobility. Choices surrounding birth may be complex in some individuals. Understanding how pregnancy will affect one's current state of health and quality of life is critical to the ongoing health of a woman with Spina Bifida.

Since menopause can cause vasomotor symptoms and changes in vaginal and bladder health, women may benefit from both lifestyle and medical management [4]. Health screening programs such as pap smears and mammograms are important for all individuals. This guideline aims to address many of the main health concerns specific to women with spina bifida, and acknowledges that since the original publication there may have been further advances in this field [5].

## 2. Guideline goals and outcomes

The goals of the Women's Health Guidelines were both practical and aspirational.

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Table 1  
Clinical questions that informed the women's health guidelines for the care of people with spina bifida

Age group	Clinical questions
6–12 years 11 months	1. When do pubertal changes happen to girls with spina bifida?
13–17 years 11 months	1. How can we manage pelvic organ prolapse in girl's age 13–17 years with spina bifida? 2. What are the sexual education needs of girls age 13–17 years with spina bifida? 3. What information and screening do girls aged 13–17 years need regarding contraception and sexually transmitted infections?
18+ years	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? 5. What is the impact of spina bifida on pregnancy? 6. How should respiratory function be monitored during pregnancy? 7. How should changes in mobility during pregnancy be managed? 8. How should bowel concerns be managed during pregnancy? How can shunt complications be assessed during pregnancy and how should they be managed? 9. How should seizure risk be managed during pregnancy? 10. What considerations should be made for bladder and kidney health during pregnancy? 11. What are considerations for birth for a woman with spina bifida? 12. Is breastfeeding impacted by spina bifida? If so, how? 13. How should vasomotor symptoms of menopause be managed by women with spina bifida? 14. How should the urogenital changes of menopause be managed by women with spina bifida? 15. How should women be screened for breast and gynecological cancers? 16. When do women/girls with spina bifida need thromboprophylaxis?

### 2.1. Primary

Provide accurate information to women with spina bifida about its impact on pregnancy and the impact of pregnancy on them.

### 2.2. Secondary

Help women with spina bifida maximize sexual functioning.

### 2.3. Tertiary

Understand menopause management options for women with spina bifida

## 3. Methods

The methodology for these guidelines has been published by Dicianno et al. [6]. The development of this guideline utilized an international expert team and systematic review of the literature. Clinical questions developed through this process are shown in Table 1. In scenarios where the evidence was limited, recommendations were based on the consensus of expert opinion. The source of the final version of these guidelines is the Spina Bifida Association Guidelines for the Care of People with Spina Bifida 2018 [7].

## 4. Results

The Women's Health Guidelines for the Care of People with Spina Bifida are shown in Table 2. Girls with spina bifida are more likely to go through puberty early [1], and will need information and support during this process. Contraception counselling may require the assessment of special circumstances, such as latex allergy, medication usage, and decreased bone mineral density, and thus individuals may benefit from consulting a gynecologist [8–11]. Health maintenance programs such as pap smears and mammograms should be encouraged and facilitated. Sexual function may be impacted by decreased pelvic sensation and challenges with orgasm. A sexologist may be helpful for some individuals [12].

Women with spina bifida may benefit from consultation with an obstetrician experienced with high-risk pregnancies to discuss the increased risk of having a baby with a neural tube defect [13], as well as an increased risk of preterm birth [14,15]. Women should be strongly encouraged to supplement with 4 mg of folic acid starting at least 1 month prior to conception, and ideally 3 months prior to conception to decrease the risk of their baby having an open neural tube defect [13]. Pregnancy care should be individualized depending on the way each woman is affected by spina bifida. Changes in pulmonary function, mobility, pain, falls [15–17], bowel and bladder func-

Table 2  
Women's health guidelines for the care of people with spina bifida

Age group	Guidelines	Evidence
6–12 years 11 months	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.	[1]
13–17 years 11 months	2. Manage pelvic organ prolapse, which can occur at any stage of life in girls and women with spina bifida, in consultation with a female pelvic medicine specialist, urologist, reconstructive surgeon or urogynecologist. Take into account the possibility of decreased pelvic sensation. 3. Provide guidance on sexual education and birth control. Contraception options should be 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. Consider consulting a gynecologist in a complex scenario. 4. Sexually transmitted infection education should include a discussion surrounding prevention through the use of non-latex condoms and HPV vaccination. Women should be made aware of availability of screening and treatment for sexually transmitted infections, and offered pap smears as per local guidelines.	[5,8,27,28]
18+ years Part A: gynecological health	5. Manage pelvic organ prolapse, which can occur at any stage of life in girls and women with spina bifida, in consultation with a urogynecologist. Take into account the possibility of decreased pelvic sensation. 6. Encourage routine gynecological care, including Pap smears and mammograms. 7. Provide guidance on sexual education and birth control. Contraception options should be 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. Consider consulting a gynecologist in a complex scenario. 8. Sexually transmitted infection education should include a discussion surrounding prevention through the use of non-latex condoms and HPV vaccination. Women should be made aware of availability of screening and treatment for sexually transmitted infections, and offered pap smears as per local guidelines. 9. Provide gynecology exam rooms and tables that are accessible for people with physical disabilities. 10. Clinicians should initiate a discussion of sexual function in a sensitive manner to facilitate 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. 11. Women with decreased pelvic sensation may find that other parts of the body, especially the lips and nipples, as well as arms, earlobes or other areas of the skin are more sensitive, and should be encouraged to explore these areas with themselves or a partner. 12. Commercially available sexual lubricants can be used to improve lubrication. 13. Women with urinary incontinence should be encouraged to catheterize or void before having sex to prevent incontinence during sex. However, some women may void during intercourse despite preventatively emptying their bladder. A discussion with the woman, and her partner if appropriate, regarding this possibility is prudent. 14. Choice of sexual positions may need to take into account level of mobility, osteoporosis and fracture risk, and respiratory function. 15. Women with spina bifida should be encouraged to communicate with their sexual partners about what they do and do not enjoy during sex.	[1,5,8–12,27–31] Clinical consensus
18+ years Part B: Antenatal care	16. Recommend preconception consultation with an obstetrician who specializes in high-risk pregnancies. Depending on a woman's medical history, she may also benefit from preconception consultation with a neurosurgeon, urologist, physiatrists, respirologist or pulmonologist, and other health care providers to discuss the potential impact of pregnancy on health. 17. Women with spina bifida are at increased risk of being pregnant with a baby with a neural tube defect. They should be strongly encouraged to decrease their risk by taking a daily oral supplement of 4 mg of folic acid starting at least 1 month but preferably 3 months prior to conception and continuing until 12 weeks of gestational age. In light of the significant risk of unplanned pregnancy, women with spina bifida of reproductive age who are sexually active may benefit from taking 4 mg of folic acid daily even when not actively planning a pregnancy. 18. Discuss the increased risk of preterm birth and review the signs and symptoms of it in the context of the person's sensory abilities. 19. Conduct pulmonary function testing at least once during pregnancy in the case of kyphoscoliosis because dyspnea can occur when there is an associated kyphoscoliosis deformity. 20. Ask about symptoms of shortness of breath at each antenatal visit, and undertake pulmonary function testing or assess for pulmonary embolism as indicated.	[1,13–24,32–37] Clinical consensus

Table 2, continued

Age group	Guidelines	Evidence
18+ years Part B: Antenatal care	<ol style="list-style-type: none"> <li>21. Consider temporary wheelchair use in individuals who use braces and crutches to ambulate, to reduce the risk of falls and subsequent trauma to parental joints and the fetus.</li> <li>22. Follow for back and leg pain and consider temporary wheelchair use and modified bedrest, massage and physical therapy if back and leg pain are severe.</li> <li>23. Consider referral to neurosurgery, orthopaedics and physical medicine and rehabilitation as needed when there are significant or concerning changes in mobility.</li> <li>24. 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 and baby care.</li> <li>25. Discuss bowel care early in the pregnancy, as pregnancy can worsen constipation. A diet high in fiber, 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 stimulate 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.</li> <li>26. Consider having a consultation with a gastroenterologist or expert in neurogenic bowel management to maximize the methods to alleviate constipation.</li> <li>27. Manage a suspected bowel obstruction with a team consisting of a general surgeon, neurosurgeon, and high-risk obstetrician. Urology should be involved in cases involving urinary tract reconstruction.</li> <li>28. 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.</li> <li>29. 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.</li> <li>30. 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 work up consists of assessing for the following: fetal well-being blood pressure proteinuria blood work to test for elevated aspartate aminotransferase (AST) and alanine transaminase (ALT) and thrombocytopenia.</li> <li>31. Optimize medical management of seizures prior to conception. Women who have a history of seizures have a higher risk of them during pregnancy and labor. If possible, avoid anticonvulsant medications that have a greater risk of teratogenicity while still providing good control.</li> <li>32. Perform regular urinalysis and urine culture tests throughout the pregnancy and treat symptomatic infections promptly. Asymptomatic bacteriuria can also progress to urinary tract infections and pyelonephritis which increases the risk of preterm birth. Management of women with a history of colonization associated with chronic intermittent catheterization (CIC) should be treated on a case by case basis when making decisions surrounding how aggressively to treat positive urine cultures. Although weekly oral cyclic antibiotics have been used successfully in some individuals who use CIC in pregnancy, there are currently no large scale trials to support this practice.</li> <li>33. Make a baseline renal assessment, ideally prior to pregnancy, or early in the pregnancy, in order to make appropriate referrals to nephrology care.</li> <li>34. 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.</li> <li>35. Perform intensified maternal and fetal monitoring in people who have renal disease in pregnancy and are at increased risk of preeclampsia and intrauterine growth restriction.</li> <li>36. Ask individuals 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.</li> <li>37. Consult with urology specialists if increased incontinence or difficulties in intermittent self-catheterization develop</li> </ol>	
18+ years Part C: Care surrounding Birth	<ol style="list-style-type: none"> <li>38. 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.</li> <li>39. 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.</li> <li>40. 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.</li> </ol>	[17,19,23–25,38–43] Clinical consensus

Table 2, continued

Age group	Guidelines	Evidence
18+ years Part C: Care surrounding Birth	<p>41. Watch for autonomic dysreflexia triggered by labor among women who have a lesion above T6. Autonomic dysreflexia can be life-threatening and those experiencing any signs or symptoms should seek emergency care and transportation to the hospital. Also there is significant clinical overlap between autonomic dysreflexia and preeclampsia, and therefore the woman should be evaluated for both.</p> <p>42. In women with previous continence procedures delivery planning may be challenging. Two approaches include a planned cesarean birth with available urology back-up if needed versus a planned trial of a vaginal birth with the associated risks of having an emergency cesarean birth. This decision should be made in conjunction with a team consisting of an anesthesiologist, urologist and obstetrician, with the individual's goals and preferences central to the planning. Keep in mind that cesarean births in people 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.</p> <p>43. Recommend a cesarean birth to protect continence for people with vesical neck reconstruction or artificial sphincter placement.</p> <p>44. Take into account that pregnancy, in and of itself, can exacerbate an existing pelvic organ prolapse and that a vaginal birth will likely exacerbate it. 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, with the woman's goals and preferences central to the planning.</p> <p>45. Consider that spina bifida can be associated with congenital renal malformations such as horseshoe kidney and pelvic kidney. If a cesarean birth is required, the surgeon should consider consultation with urology and be aware of unique renal anatomy prior to conducting the surgery if needed.</p> <p>46. Ensure that a consultant urologist be available for cesarean birth in women who have had a previous lower urinary tract surgery.</p> <p>47. Ensure that each woman has an anesthesia consultation prior to delivery to discuss the risks and benefits of regional versus general anesthesia, keeping in mind that spina bifida is not a contraindication to epidural anesthesia.</p> <p>48. Consider thromboprophylaxis on a case-by-case basis for women with limited mobility and those who use wheelchairs. Those with decreased mobility may have an increased risk of deep vein thrombosis and pulmonary embolism in pregnancy. Individuals with thrombophilia, BMI &gt; 30, smokers, pelvic girdle pain restricting mobility, those undergoing C-section or prolonged labor, preeclampsia, and preterm birth are at further risk. Consider consultation with hematology to assist with risk assessment and thromboprophylaxis duration.</p>	
18+ years Part D: Breastfeeding	<p>49. Encourage women 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.</p> <p>50. Anti-epileptic medications are, for the most part considered compatible with breastfeeding. However some require close monitoring of the baby for side effects and a reduction in the baby's exposure. Parents should be made aware of any possible side effects associated with an anti-epileptic medication they are taking while breastfeeding</p>	[26] Clinical consensus
Menopause	<p>51. 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.</p> <p>52. Medical management of vasomotor symptoms includes both hormonal and non-hormonal prescription medication. Decisionmaking surrounding which medication to take should be in conjunction with a physician experienced in managing menopausal symptoms, and take into consideration a woman's severity of symptoms, bone mineral density, risk for blood clots, and other symptoms such as depression.</p> <p>53. Women with vaginal dryness may benefit from topical vaginal lubricants.</p> <p>54. Vaginal atrophy may be treated 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.</p> <p>55. Women should be aware of their breasts, and bring any changes to the attention of their physician.</p> <p>56. Women should participate in breast cancer screening programs, which for many people will begin at age 45. This may be initiated sooner if there is a family history or other risk factors for breast cancers.</p> <p>57. Women should continue to participate in cervical cancer screening programs in accordance with local guidelines.</p>	[4,28,31,44-46]

Table 2, continued

Age group	Guidelines	Evidence
Menopause	58. Women should be made aware that abnormal vaginal peri-menopausal bleeding and post-menopausal bleeding can be a sign of endometrial cancer. Individuals should be strongly encouraged to tell their physician if they experience abnormal per-menopausal bleeding or any spotting or bleeding after menopause.	

tion [17–19], seizures [1], shunt function [20] and kidney function [21–23], may impact women differently during pregnancy. Although many may be good candidates for vaginal birth, a cesarean birth may be optimal for some individuals, a decision that should be made with input from an interdisciplinary team when warranted [15,19,23–25].

There is no specific information on breastfeeding in women with spina bifida, however those who choose to breastfeed should be encouraged to do so after reviewing their medications [26] and may wish the support of a lactation consultant. There is no specific information about management of vasomotor symptoms during menopause in women with spina bifida, however consultation with an expert in menopausal management will help take into consideration the severity of symptoms, bone mineral density, risk of deep vein thrombosis and other symptoms such as depression [4]. There is no specific data on thromboprophylaxis in women with spina bifida, however decision-making should be made on a case-by case basis for those with limited mobility or who use wheelchairs.

## 5. Discussion

This guideline was developed to help those who provide women's health services to individuals with spina bifida. Due to the diverse ways spina bifida affects each person, the concerns surrounding healthy sexual function, pregnancy, and menopausal symptoms management will be quite individualized. While performing this review, it became evident that there are limited data and multiple research gaps in the field of health of women with spina bifida. Recommendations in these areas were made based on the current small body of evidence, expert opinion, and when appropriate, extrapolating from similar groups. Screening for sexually transmitted infections, cervical cancer and breast cancer should be in concordance with local guidelines; however, it is important to recognize that women with physical disabilities face a number of systemic barriers when trying to access healthcare, resulting in decreased rates of screening.

The creation of this guideline highlighted clinically important research gaps and the need for further study. There is no information available on the effect of pregnancy on future continence or other key indicators of urogenital health in women with spina bifida. Preterm birth is an important outcome due to its significant impact on a child's health. There appears to be an increased risk of preterm birth in women with spina bifida, however more data is needed to better understand the incidence and risk factors for preterm birth in those with spina bifida. Likewise, the incidence of other important maternal outcomes including gestational diabetes, preeclampsia, and postpartum complications are unknown. There is no specific literature on breastfeeding in the context of spina bifida. Maximizing sexual functioning and management of menopausal symptoms, specifically for women with spina bifida, also requires further research. It is hoped that increased awareness of the seemingly complex overlap between women's health and spina bifida will result in increased research into this field, improving women's ability to make informed decisions about their health, and ultimately improved quality of life.

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The Spina Bifida Association has already embarked on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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