

# Caring for Persons with Spina Bifida

**Spina bifida**, which means “cleft spine,” is an incomplete development of brain, spinal cord, and/or meninges. Occurs up to 1 per 2,000 births. Types- **Closed neural tube defects** with malformation of fat, bone, membranes +/- neuro deficits. **Meningocele** has spinal fluid and meninges protruding through abnormal vertebral opening. **Myelomeningocele** has the spinal cord/neuro elements exposed. **Occulta** - silent in 10 -20 % general population.

Comorbidity	Summary	Management
<b>Function level</b>	<ul style="list-style-type: none"> <li>Mid (46%) to low lumbar (16%), hi (25%) to low sacral (10%), infreq. thoracic/cervical</li> <li>May have patchy sensory function levels</li> </ul>	<ul style="list-style-type: none"> <li>1/3 walk, 1/3 wheelchair use, 1/3 combined</li> <li>Follow up with rehab med, DME as needed.</li> <li>Verify sensation to know how pain may present</li> </ul>
<b>Hydrocephalus with CNS shunt</b>	<ul style="list-style-type: none"> <li>62-80%, 2<sup>nd</sup> cause of admissions</li> <li>Malfunction sx = HA, N/V, dizzy, lethargy, increase seizures (24% SB have seizures)</li> <li>w/ shunt - 30% IQ &gt;85, 40% IQ 70-84, 30% IQ &lt;70, higher verbal vs. visuo-perceptual scores</li> <li>More typical IQ if no hydrocephalus</li> </ul>	<ul style="list-style-type: none"> <li>Document neuro baseline, neurosurgery care.</li> <li>ED urgent radiologic assessment if malfunction suspected, compare to prior study</li> <li>Avoid excess xrays as able</li> <li>Neuropsych testing supports education &amp; planning</li> </ul>
<b>Tethered Cord Syndrome</b>	<ul style="list-style-type: none"> <li>20 - 55%, mean onset: ages 34-43</li> <li>Sx = back pain, motor weakness, continence/ scoliosis/gait/spasticity changes</li> </ul>	<ul style="list-style-type: none"> <li>Neurologic assessment for symptoms</li> <li>Avoid triggers of heavy lifting, falls</li> </ul>
<b>Neurogenic bladder and UTI</b>	<ul style="list-style-type: none"> <li>UTI - common preventable complication</li> <li>Clean intermittent catheterization, diversion surgeries</li> <li>Stones 17% - renal, bladder, ureteral</li> </ul>	<ul style="list-style-type: none"> <li>Reinforce bladder management plan, urology care.</li> <li>Distinguish asymptomatic bacteriuria vs. cystitis to limit antibiotic resistant organisms</li> <li>GFR use cystatin (<a href="https://www.kidney.org/professionals/gfr_calculator">https://www.kidney.org/professionals/gfr_calculator</a>)</li> </ul>
<b>Neurogenic bowel</b>	<ul style="list-style-type: none"> <li>Meds, enemas, antegrade enema surgeries</li> </ul>	<ul style="list-style-type: none"> <li>Reinforce bowel management plan</li> </ul>
<b>Sexual health</b>	<ul style="list-style-type: none"> <li>Erectile function &lt;=50% - +/- assoc. lesion level</li> <li>Female arousal dysfnc, avoid IUD if hx UTI's, uterine prolapse, low pelvic sensation</li> <li>Latex sensitivity/allergy -15% symptomatic</li> </ul>	<ul style="list-style-type: none"> <li>Sildenafil effective in males</li> <li>STI screen, contraception, sex ed</li> <li>Pre-conception -perinatology consult, hi dose folate</li> <li>Latex free condoms</li> </ul>
<b>Cancer Screening</b>	<ul style="list-style-type: none"> <li>Persons with disabilities lower rates of screening eg. pap smears, mammograms</li> </ul>	<ul style="list-style-type: none"> <li>Follow routine USPSTF guidelines</li> <li>Facilitate accommodations</li> </ul>
<b>Hypertension</b>	<ul style="list-style-type: none"> <li>10% &lt; age 45, 40% up to age 65, inc. w/ obesity</li> </ul>	<ul style="list-style-type: none"> <li>Screen BP routinely</li> </ul>
<b>Obesity, metabolic syndrome</b>	<ul style="list-style-type: none"> <li>Obesity 30-35%, metabolic syndrome (32%), higher with higher immobility (inc. DVT risk)</li> </ul>	<ul style="list-style-type: none"> <li>Screen BMI, segmental height or wingspan, waist circumference, counsel on healthy diet, adaptive physical activity, portion control</li> </ul>
<b>Sleep apnea</b>	<ul style="list-style-type: none"> <li>10-20% children - obstructive, central, mixed, risks: Chiari II malform (75%), lesion level, wheelchair user</li> <li>Decreased respiratory muscles strength or kyphosis/scoliosis can restrict lungs</li> </ul>	<ul style="list-style-type: none"> <li>Screen for sleep apnea</li> <li>Screen Chiari if neck pain, change in UE/LE function, swallowing, HA, ophthalmoplegia</li> </ul>
<b>Skin breakdown</b>	<ul style="list-style-type: none"> <li>Chronic skin ulcers 6%, subcut/skin infections cause admissions, most common foot, ankle, then buttocks, knee, thigh</li> <li>More in males, wheelchair users, higher lesions, shunts, bladder incontinence</li> </ul>	<ul style="list-style-type: none"> <li>Screen skin, teach home surveillance</li> <li>Address ill-fitted orthotics, incontinence, obesity, prolonged/improper seating, venous/lymphatic insufficiency, poor nutrition</li> <li>Refer to wound care as needed</li> </ul>
<b>MSK</b>	<ul style="list-style-type: none"> <li>Fractures, dislocations cause pain</li> <li>Scoliosis (50% &gt; 20 degrees) - advanced curves restrict lung function, contractures (84%)</li> </ul>	<ul style="list-style-type: none"> <li>Shared decision making for surgery w/ curve &gt; 40-50 or hip relocation</li> </ul>
<b>Mental health</b>	<ul style="list-style-type: none"> <li>Anxiety (13%), depression 25-33%, male=female rates</li> <li>Pain 25-32% adults = mental health risk factor, neuropathic pain inc. w/ age</li> </ul>	<ul style="list-style-type: none"> <li>Screen with PHQ-9 / GAD-7 if no ID, or adapted PHQ9 / GAD7 or Glasgow scales w/ ID</li> <li>Address pain, counseling, med manage, mental health w/ skills in ID</li> </ul>

Reference: Mukherjee S, Pasulka J. Care for Adults with Spina Bifida: Current State and Future Directions. *Top Spinal Cord Injury Rehab.* 2017 Spring;23(2):155-167

Summary by CYACC: April 2025

