

Care for Patients with Spina Bifida - PCP Handout

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

Key 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 Center for Youth and Adults with Conditions of Childhood in 4/25

