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Spina Bifida Through the Life Span: Management Considerations From Infancy to Adulthood

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Learning Outcomes

• Identify at least three clinical presentations of spina bifida.
• Describe at least three evidence-based therapeutic strategies for the child with spina bifida, including exercise prescription, modifications, adaptive equipment, and parent education.
• Describe at least three precautions or red flags that a therapist should be aware of when treating a patient with spina bifida.
• List at least three health complications related to spina bifida in the adult age.
Spina bifida is the term most often used to describe common congenital defects of neural tube closure (neural tube defects [NTDs]). Normally, the spinal cord and cauda equina are encased in a protective sheath of bone and meninges. In NTDs, this enclosure is incomplete. Each year, about 1,500 babies are born with spina bifida. Incidence depends on ethnic background, geographic area, socioeconomic status. Highest incidence in children of Hispanic women.
Changes in incidence

- Current incidence: approx. 1-2 children in 3,000 births
- Drop in incidence at the end of the 1990's: Folic acid
  - Supplementation for women
  - Enriched grain products / fortification
- 1,326 = Annual number of births without NTDs that would have been affected before folic acid supplementation/ fortification

Etiology and prevention

- Etiology: multifactorial
  - Genetic predisposition, teratogenic exposure, and folic acid deficiency or metabolic disorder.
- Multivitamins containing folic acid
  - Prevent 50-70% of NTDs if taken when planning pregnancy and during first 6 weeks
  - BUT folic acid must be taken prior to pregnancy to be fully effective.
Pathogenesis

- Embryonic neural groove
  - Developed 20 days post conception
  - Deepens, edges fuse to form neural tube
  - Tube closes by day 23

- Upper end closes by day 25, continues to fold and develop \(\rightarrow\) brain
- Bottom end closes by day 27 \(\rightarrow\) spinal cord.
- Along this timeline, different key processes can fail
- Even after closure, tube can reopen if CSF pressure is too high.
The most common NTDs are:

- **Spina bifida occulta** (incomplete fusion of the posterior vertebral arch)
- **Spina bifida aperta**, which includes
  - meningocoele (external protrusion of the meninges) and
  - myelomeningocele (protrusion of the meninges and spinal cord).

These defects generally occur in the lumbosacral area; but also may be found in the sacral, thoracic, and cervical areas.

https://www.youtube.com/watch?v=ouMi5z1vwbE
**Spina bifida occulta**

- Incomplete fusion of the vertebral arch
- Typically asymptomatic
  - May have bowel/bladder deficits or foot weakness
- Characteristics at level of lesion
  - Dimple
  - Hair tuft
  - Fatty deposits or cysts
  - Port wine nevi (=birthmark )

**Spina Bifida Aperta: Meningocele**

- Cyst-like bulge
- Meninges protrude outward
- Sac filled with CSF
- Typically asymptomatic
- Transillumination can differentiate it from myelomeningocele

Transillumination: light can traverse the meningocele sac, but cannot transverse a myelomeningocele sac with spinal cord tissue inside.
Spina Bifida Aperta: Myelomeningocele

- Protruding sac filled with CSF, end of spinal cord, cauda equina
- Clinical manifestations
  - Spasticity and/or flaccidity
  - Sensory disturbance
  - Bowel/bladder dysfunction
  - Musculoskeletal deformity
  - Hydrocephalus
  - Intellectual disability
  - Arnold-Chiari malformation

Clinical Manifestations

- Will depend on the type - occulta (hidden) or aperta (visible).
- Motor dysfunction depends on the level of involvement.
- 75% of defects are located in the lumbosacral region
  - L5-S1 level most common.
• Unevenly distributed loss of motor function
  ◦ Muscle imbalance
  ◦ Scoliosis
  ◦ Musculoskeletal deformity
• Infants: truncal hypotonia and delayed automatic postural reactions.
  ◦ This may occur even in sacrum-level lesions.
• Sensory disturbances
• Bowel/bladder problems
  ◦ Urinary incontinence, infection
• Increased risk for pressure ulcers

**Hydrocephalus**

• 90% of children with myelomeningocele
• Usually happens with a type I or type II Arnold-Chiari malformation
  ◦ Cerebellar tonsils through foramen magnum – obstruction of CSF flow
Cognitive considerations

- Many children with spina bifida have difficulties with:
  - perceptual organizational abilities, attention, speed of motor response, ocular function, memory, efficiency of processing, conceptualization, and problem solving.
- 1/3 of children with myelomeningocele and shunted hydrocephalus also have intellectual disability, usually mild.

General Prognosis

- Very variable!
- Worse in children with:
  - total paralysis below lesion,
  - kyphoscoliosis,
  - hydrocephalus,
  - loss of renal function
- Survival to adulthood ~85%
  - Complications with growth are common
  - As adults, patients with myelomeningocele still need treatment (deformities, pain, pressure ulcers, psychological issues, neurological complications)
Prognosis for Motor Function

- Depends on level and type of lesion
- Even for low level lesions, typically delays in achieving ambulation.
  - Not likely to ambulate if haven’t achieved it by age 7 to 9.
- Prognostic indicator: if able to walk outdoors by age 7, good ambulation prognosis.
- Decline in ambulatory status in pre-teen/teen years is common

EVERY PATIENT WITH SPINA BIFIDA WILL BE DIFFERENT
- Focus on their particular abilities, strengths, and weaknesses
Spina Bifida Association

- Spina bifida association is an outstanding resource!!
- [http://spinabifidaassociation.org/project/](http://spinabifidaassociation.org/project/) has many downloadable pdf files in English and Spanish
- Handout: “How spina bifida lesions impact daily function”
### International Myelodysplasia Study Group Criteria for Assigning Motor Levels

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Possible Muscle Strength</th>
<th>Possible Orthopedic Complications</th>
<th>Possible Cognitive Dysfunction</th>
<th>Possible Equipment Modification</th>
<th>Possible Cognitive, Communication Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2</td>
<td>Minimal involvement, mild, and functional improvement possible</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>3-4</td>
<td>Moderate involvement, significant improvement in motor function expected</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
</tr>
<tr>
<td>5-6</td>
<td>Severe involvement, significant improvement in motor function unlikely</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
<td>Orthopedic abnormalities, possible scoliosis, etc.</td>
</tr>
</tbody>
</table>

- **International Myelodysplasia Study Group**
- **Criteria for Assigning Motor Levels**
MEDICAL AND SURGICAL MANAGEMENT OF SPINA BIFIDA

Overview of spina bifida diagnosis and medical management

• Diagnosis
  ◦ Prenatal screening
    ◦ Ultrasound
    ◦ AFP protein testing
    ◦ Amniocentesis
    ◦ Fetal MRI
  ◦ Postnatal clinical eval
Medical Management

- Cesarean section (to reduce birth trauma)
- Fetal repair/closure
- Postnatal repair/closure
- VP shunt placement
- Orthopedic surgical corrections
  - High incidence of clubfoot
  - Spinal deformities
  - Hip dislocation
  - Other deformities
- Symptom management

Repair

- Fetal
  - Decreases incidence of hydrocephalus and Arnold Chiari malformation
  - MOMS trial: Better standardized test scores for motor skills and higher chance of independent walking at 30 months compared to postnatal surgery
  - https://www.youtube.com/watch?v=qRtspxmhYnA
- Postnatal
  - Within 48 hrs of birth
  - Higher risk of infection and complications
**Shunts**

- Drain CSF from the ventricles
  - Ventriculoatrial, ventriculoperitoneal
- Prevent backflow
- Have room for growth
- Superficial
  - Handling precautions

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**Orthopedic management**

- As the child grows, orthopedic surgical interventions may be needed
  - Deformity and malalignment as result of muscle imbalance
  - Other orthopedic issues
- Examples:
  - Tendon releases for hip and knee contractures
  - Clubfoot surgery, congenital vertical talus surgery
  - Spinal fusion for spine deformities (controversial); kyphectomy (may improve sitting balance)
  - Hip surgery for unilateral dislocation

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**CONTINUED**
Bowel and bladder management

- Spastic or flaccid bladder
  - Spastic - Potential damage to upper urinary tract and kidneys
  - Flaccid – Prone to infection
  - Intermittent catheterization, electrical stimulation, medication

- Treatment of bowel incontinence
  - Nutritional
  - Pharmacological

PRECAUTIONS AND RED FLAGS IN PATIENTS WITH SPINA BIFIDA
Precautions: sensory loss

- Must assess sensory function in extremities
  - Sensory levels often do not correlate with motor levels
- Protect against possible injury
  - E.g.: hot water

Precautions: latex allergy

- Very common in these patients! ~75%
- Signs: watery & itchy eyes, sneezing, coughing, hives, rash, swelling of trachea, BP changes, circulation changes, anaphylactic shock
- Therapist: no latex toys or latex items that could be put in mouth.
- Do you know which items in your clinic or hospital have latex? - Handout
- Educate parents on carefully reading all labels and inspecting item composition.
**Precaution: Increased risk for pressure ulcers in myelomeningocele**

- Incontinence
- Sensory loss
  - Friction burns in active kids
  - Pressure from casts or orthoses
- Malalignment from scoliosis and other ortho deformities
- Vascular issues
- Obesity and poor transfer skills

**Precaution: low bone density**

- Increased risk for fractures
  - Incidence: 11-30% in myelomeningocele
  - > common if wheelchair-dependent, higher neuro level (?)
    - Some recent studies question this.
- Diagnostic challenges
  - Sensory loss
  - Swelling, warmth, low grade fever may be only signs.
It’s a fine balance...

- We want to avoid fractures...

BUT

- We want them to be active
  - Mechanical stresses and muscle tension on bone help increase bone density - “Wolff’s law”
  - Not moving reduces muscle strength and bone mass.
  - Not moving makes children fearful of moving and being moved, and it also makes them functionally dependent.

Be alert: Hydrocephalus

- Be aware of s&s of increased CSF pressure
- Shunts can become obstructed or fail
- Red flags:
  - In infants, bulging fontanelle, fever, irritability, seizures.
  - Once skull fused: headache, vomiting, irritability, sleepiness, seizures, fever, ataxia, confusion, etc.
Be alert: Arnold-Chiari malformations

- Severe Arnold-Chiari malformations can be fatal.
  - Central apnea.
  - Cranial nerve involvement

Be alert: Tethered Spinal Cord

- 3% to 5% of children with spina bifida
- Adhesions anchor spinal cord, which is not free to move and reposition – what happens as child grows?
- Cord is stretched – metabolic changes, ischemia → signs and symptoms
Tethered spinal cord

- Signs/red flags:
  - Rapidly progressive scoliosis, hypertonia in lower extremities, asymmetric changes in muscle strength with strength decline in some areas, changes in gait pattern, changes in urologic function, discomfort in spinal area.
- Requires surgical repair

Be alert: Hydromyelia

- Pockets of excess CSF, dilation of central canal
  - Areas of increased pressure and necrosis
  - Affects surrounding peripheral nerves
- Red flags: Progressive extremity weakness, hypertonia, scoliosis
- Requires shunting
EVIDENCE-BASED THERAPEUTIC STRATEGIES TO IMPROVE FUNCTIONAL OUTCOMES IN CHILDREN WITH MYELOMENINGOCELE

Framework for our discussion
International Classification of Functioning, Disability and Health (ICF)

- Health Condition (disorder/disease)
- Body function & structure (Impairment)
- Activities (Limitation)
- Participation (Restriction)
- Environmental Factors
- Personal Factors

Contextual Factors
What’s the end goal of therapeutic intervention?

- The long-term goal is independence in all life functions (e.g., self-care, locomotion, recreation, social interaction, and work/school/play), with adaptive devices as needed.

Overarching role of PT

- Addressing delayed motor development
- Addressing musculoskeletal dysfunction
- Pre and post-surgery, or post-fracture
- Consultation about safe activities, environmental adaptations and adaptive/assistive equipment
- Learning a new skill or adapting the way a skill is performed
Motor development

- Developmental motor skills impaired due to:
  - Motor and sensory loss
  - Weakness
  - Over time, deformity
  - BUT ALSO LACK OF OPPORTUNITY!

Consider: Perceptual Motor and Cognitive Performance

- Range of cognitive levels
  - Other CNS abnormalities?
  - Was hydrocephalus treated expeditiously?
  - Were there other insults to the CNS (e.g. infection)?
  - Presence of intellectual disability or cognitive processing issues.
Therapeutic Interventions

- Role of PT
  - Assess for initial determination of motor level; monitor progress
  - Promote motor development and active functional movement
  - Prevent or minimize deformities that interfere with function
  - Promote strength, ROM, balance, and coordination for transfers and mobility
  - Plan mobility program for ambulation or wheelchair use
  - Make recommendations for use of orthotics
  - Monitor for complications
  - Parent education

Key factors determining care

- Age
  - Infant
  - Toddler/preschool
  - School
  - Young adult and beyond
- Level of function
  - Thoracic level
  - High lumbar level (L1-L3)
  - Low lumbar level (L4-L5)
  - Sacral level
- Presence of complications
**Remember: mobility expectations**

<table>
<thead>
<tr>
<th>Level</th>
<th>LE motions</th>
<th>Orthoses</th>
<th>Ambulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>T12</td>
<td>Absent</td>
<td>Stander, HKAFO</td>
<td>Therapeutic</td>
</tr>
<tr>
<td>L1-L2</td>
<td>Hip flexion, add</td>
<td>HKAFO, RGO, KAFO</td>
<td>Household (short distances)</td>
</tr>
<tr>
<td>L3-L4</td>
<td>Knee extension</td>
<td>KAFO, AFO</td>
<td>Household, short distances in community</td>
</tr>
<tr>
<td>L4-L5</td>
<td>Hip abduction, some knee flexion, dorsiflexion</td>
<td>AFO</td>
<td>Household, short distances in community</td>
</tr>
<tr>
<td>S1</td>
<td>Hip extension, strong knee flexion, foot eversion</td>
<td>AFO, SMO, Shoe orthosis or nothing</td>
<td>Community</td>
</tr>
<tr>
<td>S2-S3</td>
<td>Plantarflexion</td>
<td>Shoe orthosis or nothing</td>
<td>Community</td>
</tr>
</tbody>
</table>

**Newborn and Infant**

- Initial assessment and establishment of a baseline
- Ongoing assessment of strength, ROM, function (pre-op, post op day 10, 6 months, and yearly)
- Plan of care
  - Developmental Milestones
  - Positioning
  - Range of Motion/stretching
  - Strength
  - Orthoses
  - Parent Education
Initial Assessment:

- Manual Muscle Testing:
  - Baseline and monitoring
  - Provides level of function - Motor level = lowest level with antigravity movement
  - Consider functional assessment based on age
    - Example: observe active leg kicking and palpate quadriceps to assess function.
    - Young child: anti-gravity positions; older child can do traditional MMT
  - May have to use present/absent rather than traditional grades
  - Consider alternate positions based on surgery precautions.

- Muscle tone
- Range of motion
  - At full term, hip/knee flexion and foot DF contractures are normal for healthy infants
  - But these may be accentuated in a child with spina bifida
    - Hip flexion due to unopposed hip flexors
    - Ankle DF due to unopposed dorsiflexors
  - Determine need for modified positioning, ROM exercises

- Sensory Assessment
- Skin Assessment
Surgical management of the newborn and role of PT

- Evidence that early management yields better outcomes
  - Closure within 48-72 hours after birth
- PT involved in pre-op assessment
  - Team: Urology, neurology, neurosurgery, pediatrician, neonatologist, orthopedist, PT, etc.
- 24-48 hrs post-surgery, start PT focusing on ROM

Developmental positioning and handling of the infant

- Provide developmental experiences
  - Varied positions, opportunity
  - Prevent compensatory strategies for low tone/proprioceptive input
  - Work on equilibrium and righting reactions
- Educate parents on handling their infant
  - Emphasize developmentally-appropriate positions, with adaptations if needed.
  - Examples:
    - Carry child high on shoulder – movement of head and correct positioning of UEs
    - Promote symmetric midline posture during play activities
    - Use sitting activities to challenge balance responses
    - WB in developmental positions
• Use a variety of holding positions and promote symmetry
  – Parent participation in experiences!
• Do not use baby walkers or jumpers
Therapeutic interventions

- Developmental weight-bearing activities important to keep ROM & mobility
  - Prone, supine, side-lying
  - Rolling & floor mobility
  - Sitting & pulling to stand (with orthoses if needed)
    - Standing frame / HKAFO
  - Ambulation with assistive device once able

- Use standardized developmental assessments to monitor progress (Peabody, etc)

Use proximal key points of control to enhance stability
Toddler and preschool age

- Developmental milestones, gross motor development
- Positioning, standing
- ROM and strength
- Mobility, ADL’s, assistive devices, orthoses
  - Preschooler should have increasing independence
  - Power mobility training can start very early!
- Continue providing opportunity for exploring the environment
- Prevent complications
- Continued assessment to identify strengths and weaknesses

- Continue active strengthening through play. Play is therapy!
- Some activity ideas for preschoolers:
  - Straddle-roll activities with therapist facilitating or stabilizing at the pelvis
  - Scooter-board activities
  - Riding tricycles
  - Playground games (Follow the Leader)
  - Ball activities
  - Pool activities with floats
• Thoracic level
  ◦ No active lower extremity muscles
  ◦ Function: rolling, sitting, commando crawl, wheelchair

• High lumbar level
  ◦ Hip flexion contractures, hyperextended trunk, no active hip extension
  ◦ Function: prone, quadruped pull to kneel, sit hands free
  ◦ Ambulation: RGO and HKAFO with crutches or walker; may be able to use KAFO

• Typical ambulation sequence for T12-L3
  ◦ Preambulation: Toronto A frame
  ◦ For high lumbar and thoracic with mild-moderate CNS status, assess ambulation orthoses at 15-24 months
  ◦ Start with:
    ◦ Mild: HKAFO locked hips, walker
    ◦ Moderate: RGO, thoracic uprights, walker
    ◦ Severe: swivel walker
  ◦ Progress to:
    ◦ Mild: unlock hips, then crutches, then KAFO
    ◦ Moderate: remove uprights, crutches, HKAFO or KAFO
    ◦ Severe: RGO, thoracic uprights, walker
• Low lumbar level L4-L5
  ◦ Hip abduction, knee extension, some knee flexion, some dorsiflexion
  ◦ Crawling is a good training activity
  ◦ Ambulation: household and community using KAFO or AFO
• Sacral level
  ◦ S1 has strong DF and eversion contractures (PF starts emerging at S2)
  ◦ Hip extension is now available – crucial
  ◦ Ambulation: 12-14 months, independent by 5 years, walker to crutches to no device, some need shoe orthosis, some don’t.

• Typical ambulation sequence for L4-L5 and sacral
  ◦ Preambulation:
    ◦ Lumbar: Toronto A frame, some children may pull to stand with orthoses
    ◦ Sacral: no preambulation orthoses needed
  ◦ Ambulation:
    ◦ Lumbar: KAFO if weak quadriceps, or AFO. Start with walker and progress to crutches.
    ◦ Sacral: AFO if crouch gait, shoe insert or nothing. May or may not need assistive device.
School age

- Continue plan of care:
  - Positioning, ROM (stretching, serial casting?), strength, prevention of secondary impairments

- Increased independence
  - ADL’s: transfers, self care
  - Mobility
  - Recreation
  - School activities

- Assistive devices, orthoses, WC, seating system as needed

- Physical activity important for cardiovascular health
- Encourage participation in peer activities with necessary adaptations
- Maintain proper alignment, strength (including core), and endurance
- Manage deformities
  - Consider modifications to mobility equipment to accommodate deformities.
- Match their interests – adaptive sports activities, aquatic activity, customized programs
  - Let them decide, but guide
Treadmill training

- De Groot et al study:
  - 32 ambulatory school-aged children with SB, 18 did supervised treadmill training for 12 weeks at home and 14 did usual care.
  - Patients in home training exercised twice a week at an intensity of 66% of HRmax and gradually progressed from 70% to 140% of their individual walking speed.
  - Treadmill training group showed improvements in 6-minute walk test, gait speed, and VO2peak
  - Effect on 6MWT and gait speed still present 3 months post intervention
    - 30% had kept doing treadmill, 30% had taken up other forms of physical activity

Evaluating exercise response (de Groot, 2011)

- Ambulatory children with spina bifida have lower levels of aerobic endurance as measured by incremental exercise testing.
- Both maximal and submaximal measures of exercise testing can be used in this population.
- Peak measures are superior to submaximal measures.
- HR measures more reliable than oxygen measures, and functional outcomes (treadmill speed and 6MWT distance) being the best at detecting change.
Orthoses:
Two fighting schools of thought

- Based on motor level, we can predict mobility.
  - “Reasonable” expectations for each child
- Optimal level of performance is dictated by more than motor level
  - Early standing and gait training whenever possible

What is agreed upon

- Team should establish a clear orthotic approach from day 1
- Early management should combine orthoses and positioning, in a manner consistent with the overall approach.
- Child should be prepared for upright positioning in a developmental sequence.
- 3D gait analysis is a useful tool together with MMT to assess orthotic needs
• Evidence: “Children whose programs emphasize upright activities and ambulation show better outcomes in transfer skills, greater bone density, fewer lower extremity fractures, and a smaller incidence of pressure ulcers.”
• Evidence: “High-level lesions do not preclude ambulation; however, this may be an energy-intensive activity compared with wheeled mobility and may have a negative impact on aspects of school performance.”
• Evidence: “Some data support the efficacy of using ankle-foot orthosis and crutches for gait and walking outcomes at the body functions and structures level of the ICF-CY. Potential benefits at the activities and participation level have not been properly investigated.”

A total-contact orthosis can be worn at night, and can have wedged soles for standing and weight-shifting activities.

Standing programs 5 days per week positively affect bone mineral density (60 to 90 min/d); hip stability (60 min/d in 30° to 60° of total bilateral hip abduction); range of motion of hip, knee, and ankle (45 to 60 min/d).
Gait training with a reciprocating gait orthosis.

RGO with thoracic band and uprights

RGO can be combined with body jacket to manage scoliosis
HKAFO with walker

Twister cables added to an AFO to control in-toeing
• Adapted strollers for young children
• Standard wheelchair by school age
• Power wheelchair and scooters as child ages

The young adult and beyond

• Independent living skills
  ◦ Household and community ambulation with assistive device, or manual or powered mobility
• Personal goals: work, study. Help with task-specific strategies
• Educate on life-long health strategies
  ◦ Have a transition plan
  ◦ Understand the importance of managing health throughout the lifespan
  ◦ Educate on complications and issues in adulthood
The young adult and beyond

- Aging process compounds on existing issues
  - May see functional decline
  - Example: ambulation deteriorates over time
    - Need to make sure they have access to wheelchairs, assistive devices or orthoses to maintain mobility and participation

- Common problems:
  - Obesity, incontinence, recurrent urinary tract infections, chronic ulcers, joint pain, hypertension, neurologic deterioration, sexual difficulties, and depression
  - Most common cause of morbidity: urinary tract issues

- Bowel and bladder:
  - Neurogenic bladder continues to be an issue through the lifespan. Also, increased risk of bladder cancer?
  - Risk for renal failure 8 times greater than in the general population
  - Most adults with spina bifida have abnormal bowel function.

- Continue to monitor for shunt complications, tethered spinal cord, hydromyelia, latex allergy
  - Late-onset shunt failure - sudden death
  - Subtle shunt malfunctions can affect cognition, self-management and independence.
• Musculoskeletal
  ◦ Shoulder pain, wrist pain
    ◦ Assistive device and wheelchair use
    ◦ Shoulder pain is less in those who have used wheelchair since childhood.
  ◦ Low back pain
    ◦ Scoliosis
    ◦ Evidence: No change in quality of life measures after surgery…
  ◦ Knee and hip contractures
  ◦ Hip dislocation
  ◦ Need to make sure wheelchair and assistive devices continue to properly fit and adjust to patient needs.

• Increased risk for sleep apnea
  ◦ How does this affect shunt function? More research needed.
  ◦ Cognitive impairments, insulin resistance, obesity, cardiopulmonary problems…
• Increased risk for chronic headaches
• Early-onset osteoporosis (50%)
  ◦ Hip more affected than lumbar spine
• Sexual health issues
  ◦ http://spinabifidaassociation.org/project/health-care-for-women/
  ◦ http://spinabifidaassociation.org/project/mens-health/
Interested in knowing more?

- Spina Bifida Association Webpage
  http://www.spinabifidaassociation.org/
- Article on health issues in the adult with spina bifida

Health and life facts: why this issue needs attention!

- Admission rates 9 times higher than general population
  ◦ 47% of the admissions to one acute care hospital involving adults with SB were secondary to preventable conditions (Kinsman and Doehring).
- 76% do not have primary care provider.
- Medical expenditures 3-6 times greater than those without SB
- Need lifelong integrated care
- Individuals with childhood disabilities in general are underemployed and not consistently living independently as adults.
  ◦ Study: Only 29–33% of adults with SB were in competitive employment - could this be improved if preventative care was better??
Transition to adult care

• 5 key elements necessary for the successful transition of care (Binks et al):
  ◦ Early preparation/education of the individual and family,
  ◦ Flexible timing of the transition,
  ◦ Introduction to the transition clinic,
  ◦ Interested adult-center providers,
  ◦ Coordinated transfer of care approach between the individual, family, pediatric primary care physicians, and adult specialist.

• Barriers:
  ◦ Child healthcare providers or parents refusing to “let go”
  ◦ Reluctance to leave a family-centered care paradigm
  ◦ Adult center care providers having limited knowledge or limited interest

Have a plan from day 1!!!
Be an advocate