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Shared Decision Making in Spina Bifida

The Longitudinal Neurosurgical Relationship

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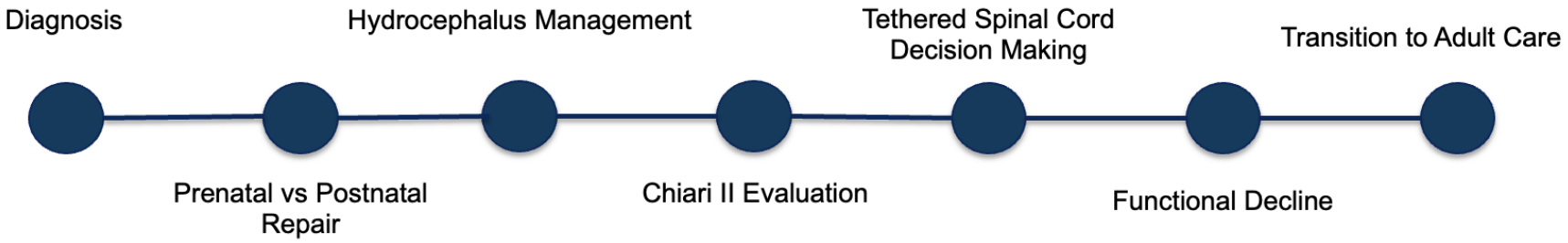
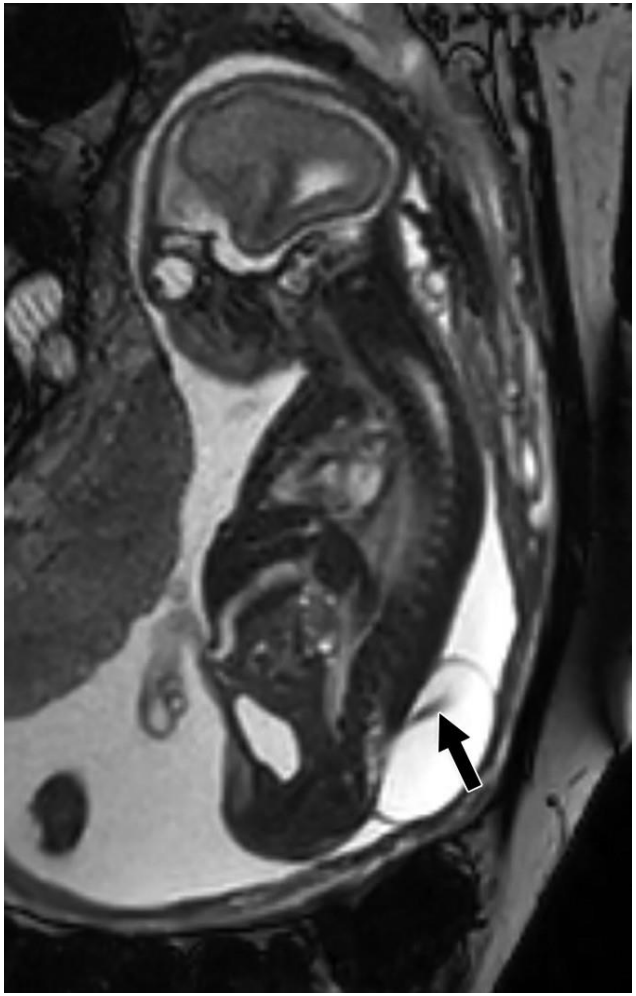
*The care of patients with spina bifida is **not** defined by a **single** operation, but by a **series of decisions** made across a **lifetime**.*

Decision Points Across the Lifespan



Prenatal Diagnosis

The First Major Decision



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Fetal vs Postnatal Repair

Fetal Repair

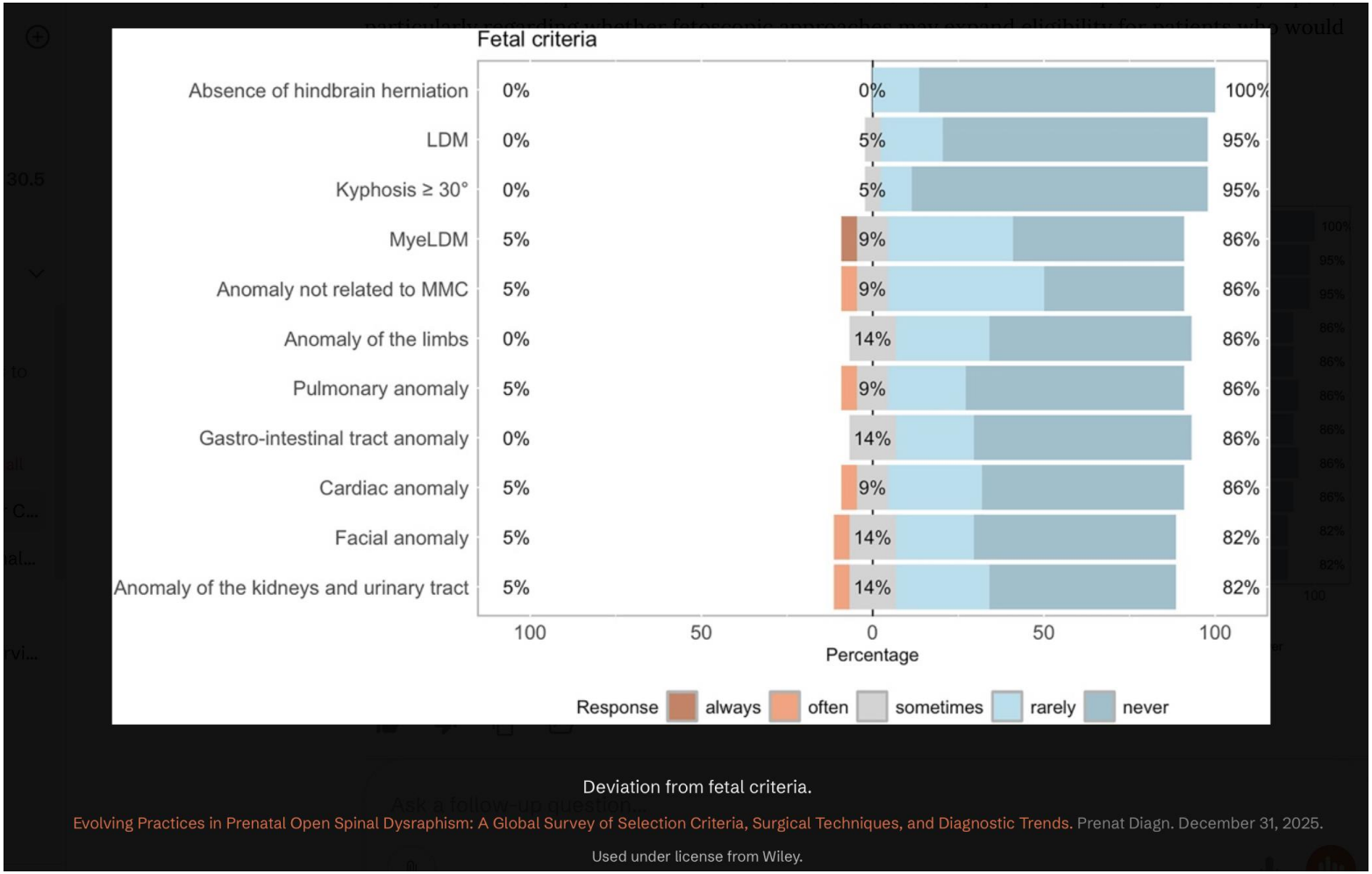
Reduced shunt requirement
Improved ambulation
Reduced hindbrain herniation
Maternal morbidity
Prematurity risk
Future obstetric implications

Postnatal Repair

Avoids maternal surgical risk
Standardized postnatal pathway
Higher shunt rates
Less hindbrain herniation reversal
Lower independent ambulation rates

The decision is not between a good option and a bad option. It is between different risk profiles, uncertainties, and hoped-for outcomes.

From Protocol to Personalized:
Rethinking MOMS Trial Criteria in 2026



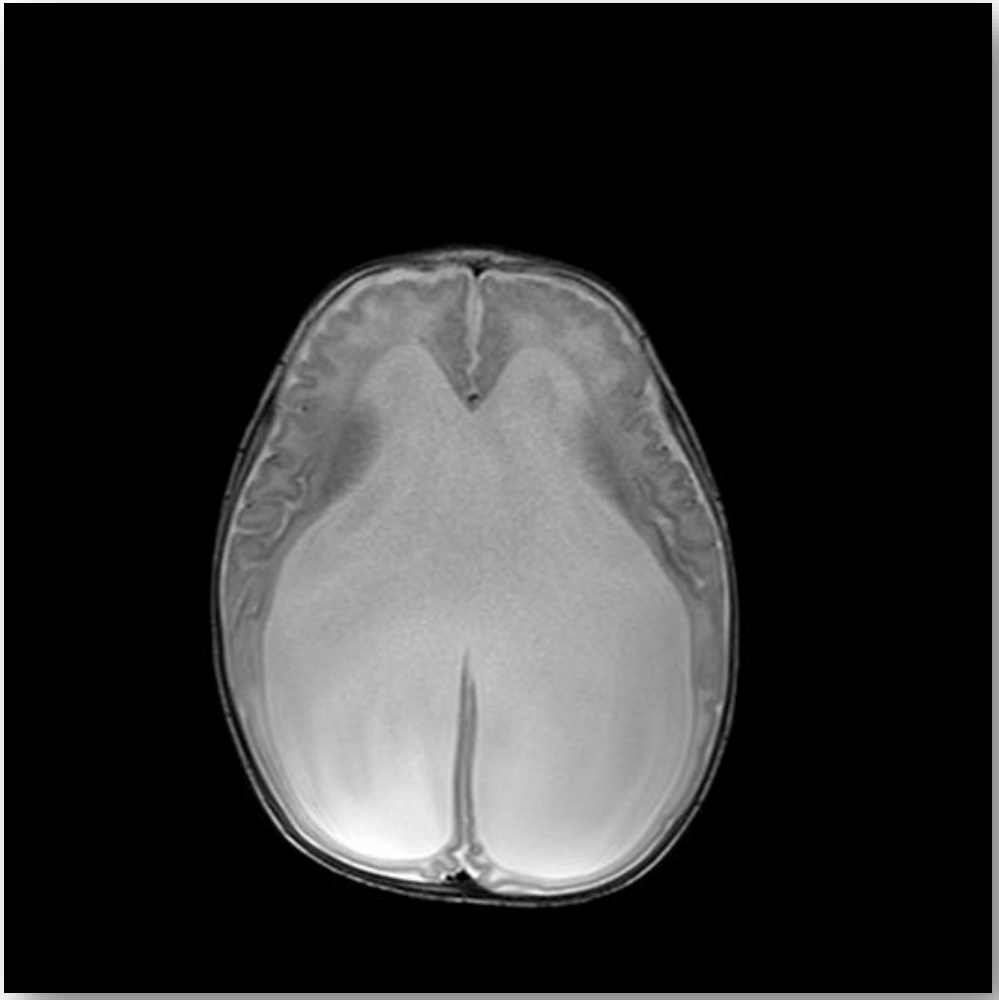
Deviation from fetal criteria.

Evolving Practices in Prenatal Open Spinal Dysraphism: A Global Survey of Selection Criteria, Surgical Techniques, and Diagnostic Trends. Prenat Diagn. December 31, 2025.

Fetal Surgery Changes Probabilities,
*Not **Destinies***

Hydrocephalus

The Central Neurosurgical Challenge



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Hydrocephalus

Prenatal Repair	Postnatal Repair
Lower Shunt Rate	Higher Shunt Rate
Later Presentation	Earlier presentation
Continued lifelong surveillance	Earlier CSF Diversion

CSF Diversion

Shunt vs ETV/CPC

Ventriculoperitoneal Shunt

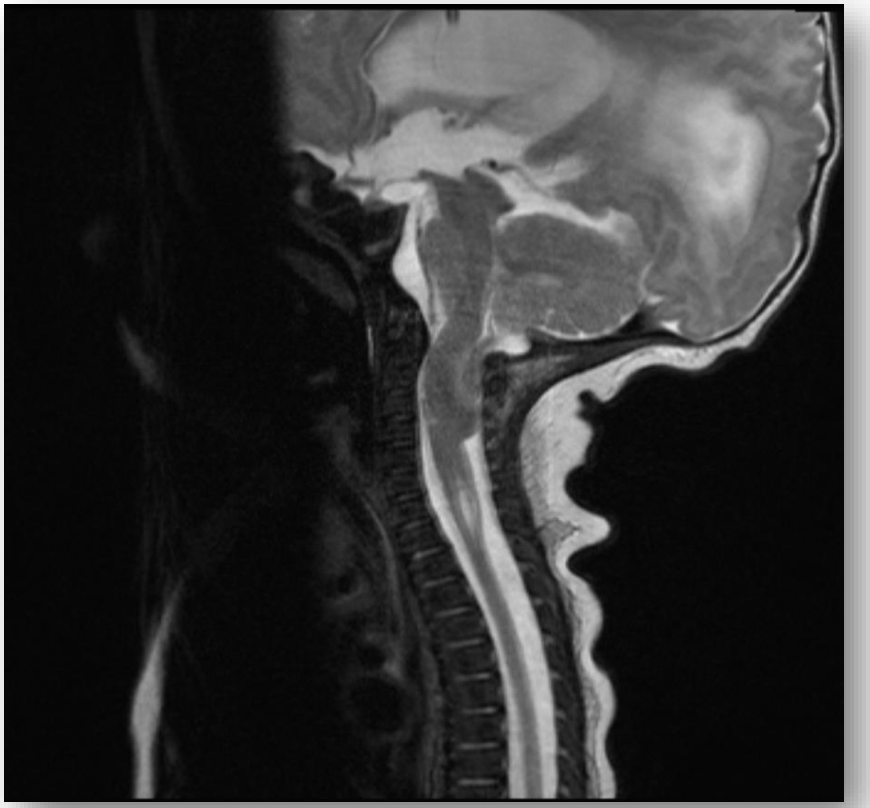
Familiar pathway
Immediate reliability
Lifelong device dependence
Revision burden

ETV/CPC

Potential shunt independence
Variable durability
Age dependent outcomes
Institutional variability

We are not simply choosing an operation. We are choosing a long-term management pathway.

Symptoms Matter More Than Imaging

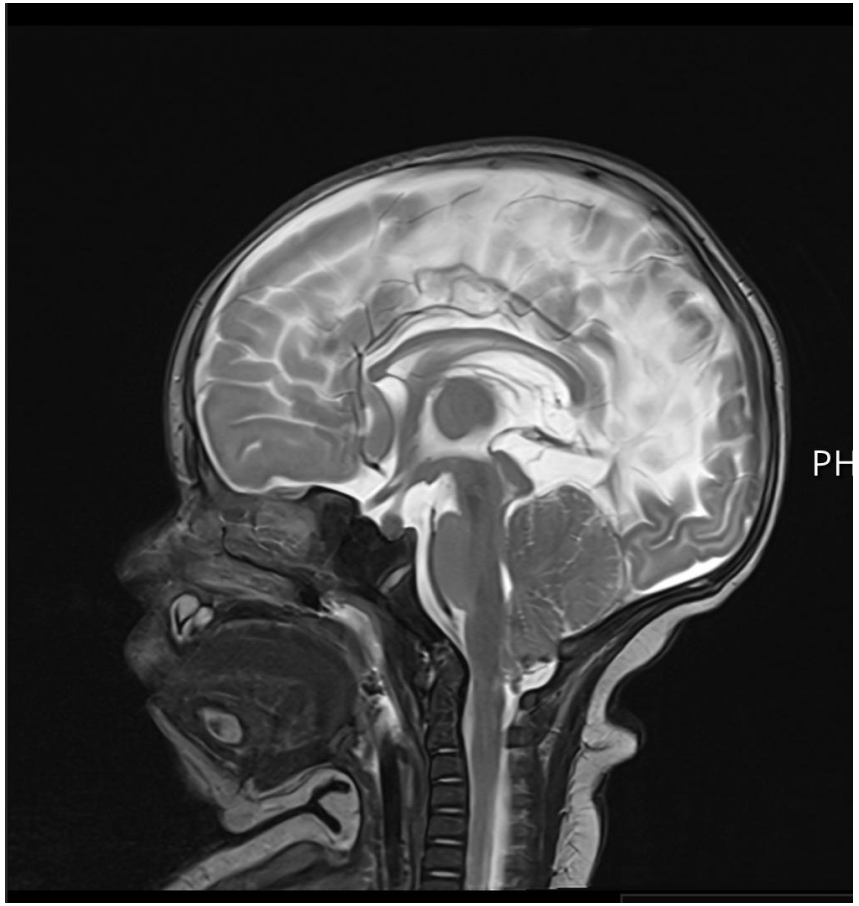


Imaging abnormalities common

Clinical deterioration drives intervention

Chiari II Evaluation and Management

- Brainstem dysfunction
- Swallowing abnormalities
- Respiratory compromise
- Stridor/apnea
- Upper extremity findings
- Evaluate shunt function first



Longitudinal Follow Up

Surveillance as Shared Decision Making

annual evaluations

multidisciplinary clinics

serial neurologic exams

gait evolution

bladder changes

orthopedic progression

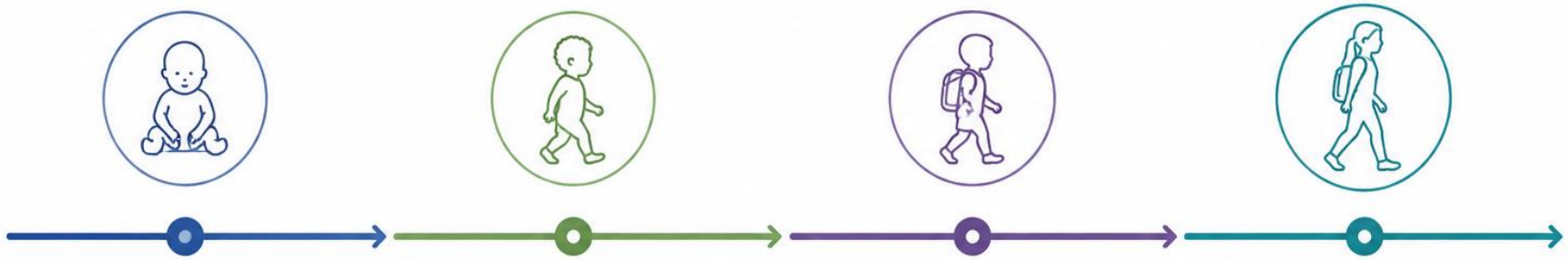
developmental changes

subtle parental observations

Longitudinal Follow Up

Surveillance as Shared Decision Making

Many of the most important neurosurgical decisions in spina bifida are not made during crises. They emerge gradually through longitudinal observation.



Infancy
Shunt surveillance

Early Childhood
Development and mobility

School Age
Bladder and gait changes

Adolescence
Independence and transition

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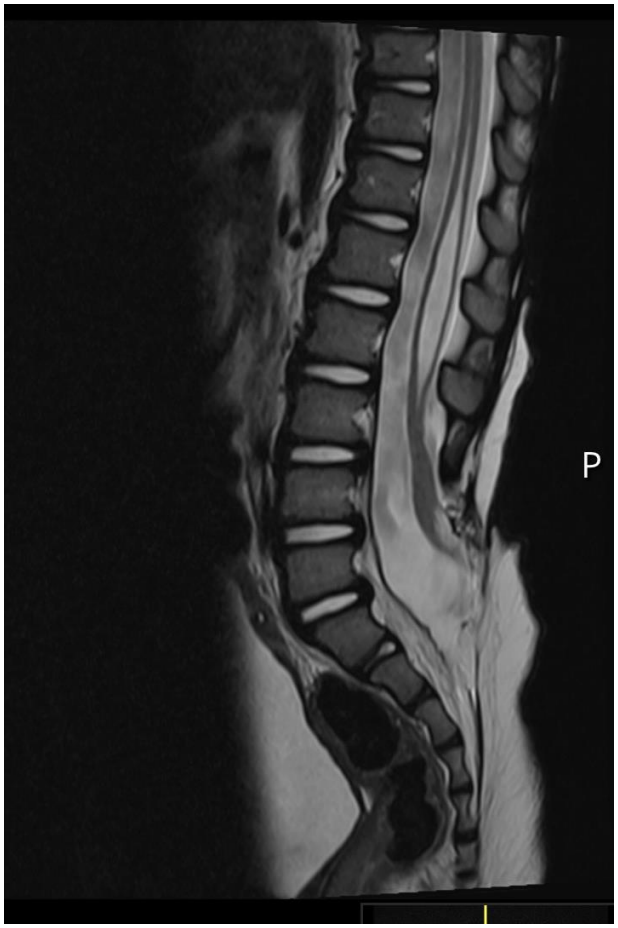
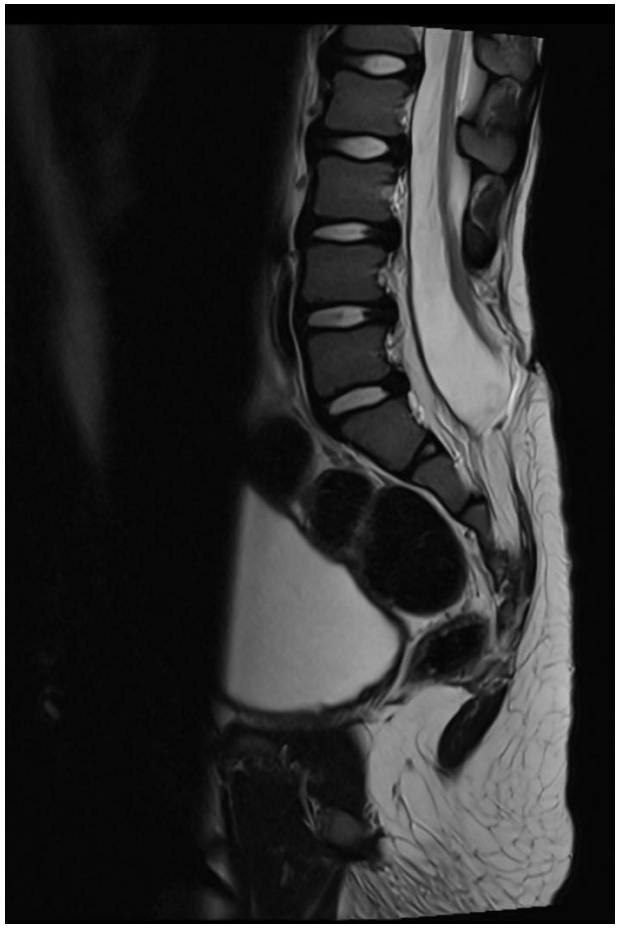
Tethered Cord

The Difficult Margin Between Observation and Intervention



The question is often not whether surgery is possible, but whether this is the right moment.



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What Raises Concern for Tethering?

Declining bladder function

Gait deterioration

Progressive weakness

Pain

Sensory changes

Orthopedic progression

Functional decline in spina bifida is not normal until proven otherwise.

Shared Decision Making in Tethered Cord Care

Observe

- Stable neurologic function
- Equivocal symptoms
- Prior multiple untetherings
- Concern for surgical morbidity
- Uncertain benefit

Operate

- Progressive functional decline
- Urologic deterioration
- Loss of ambulation
- Progressive weakness
- Concern for irreversible injury

*In many patients, the goal of surgery is **stabilization** rather than **restoration**.*

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Transition to Adult Care

The Next Longitudinal Challenge

Successful transition is not simply transfer of care.
It is the development of autonomy, continuity, and self advocacy.

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Transition of Care is Far from Ideal

JNS PEDIATRICS

CLINICAL ARTICLE

J Neurosurg Pediatr 25:555–563, 2020

Health care transition in pediatric neurosurgery: a consensus statement from the American Society of Pediatric Neurosurgeons

Brandon G. Rocque, MD,[1] Bradley E. Weprin, MD,[2] Jeffrey P. Blount, MD,[1] Betsy D. Hopson, MSHA,[1] James M. Drake, MBBCh,[3] Mark G. Hamilton, MD,[4] Michael A. Williams, MD,[5,6] Patience H. White, MD, MA,[7] Katie O. Orrico, JD,[8] and Jonathan E. Martin, MD[9]

The Multidisciplinary Relationship

The Dallas Way

Neurosurgery

Urology

Orthopedics

PM&R

Developmental Pediatrics

Psychology

Therapy Services

Social Work

Care Coordination

The multidisciplinary clinic is not ancillary to good care.
It is the infrastructure that allows longitudinal care to exist.

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Shared decision making in spina bifida is not a single conversation, a single operation, or a single moment in childhood.

It is a longitudinal process built on trust, surveillance, multidisciplinary partnership, evolving goals, and honest navigation of uncertainty across a lifetime.