Options for Pregnancies Affected by Spina Bifida

It is very important that you feel you have all of the information you need about your baby's condition and all your options to help you decide your next steps. This often requires additional testing and referrals to specialists such as a pediatric neurosurgeon or fetal surgery center.

Your options include:

- Fetal Surgery
- Postnatal Surgery
- Adoption
- Termination

There is no one best option for each family. Any decision parents make with love, information, and empowerment is the right decision.

SPINA BIFIDA ASSOCIATION

Fetal Surgery for Spina Bifida

Treatment for open Spina Bifida may occur during the pregnancy or shortly after the baby is born. Closing the baby's back during the pregnancy can protect the spinal cord from further damage and decrease the risk of developing progressive hydrocephalus (extra fluid on the brain). Fetal surgery is not a cure, and it comes with both benefits and risks.

Evaluation

The evaluation for fetal surgery will involve tests such as ultrasounds, fetal echocardiogram to take pictures of the baby's heart, an MRI (magnetic resonance imaging) to get detailed images of the baby, an amniocentesis (where some amniotic fluid is removed from uterus), and others.

There are guidelines for who is and who is not a good candidate for fetal surgery. Each case is evaluated carefully for the safety and benefit of both the mother and the baby. If you meet all inclusion criteria, specialists will then help you decide if fetal surgery is an option for your specific situation. For those who are not eligible or choose to not have fetal surgery, the baby's back can be surgically closed shortly after birth.

Patients may be eligible for fetal surgery if they meet all of the following criteria:

- Confirmed Myelomeningocele between T1 and S1 area on the spine
- Hindbrain herniation, which is part of Chiari II Malformation, where the back part of the brain is pulled down into the spinal column
- Pregnancy between 19 and 26 weeks (sometimes later) at time of surgery
- Mom's age is 18 years or older
- Carrying only one baby
- Normal fetal echocardiogram
- Normal chromosomes

Patients may not be considered good candidates if:

- Baby has serious medical problems besides those related to Myelomeningocele
- There is a significant curve in the baby's spine
- Mother has a high BMI (body mass index) which means she may be overweight. BMI limits may vary by center
- Medical issues with mom's uterus, cervix, infections, alloimmune conditions, or other reasons that would prevent abdominal surgery or anesthesia
- Lack of physical, mental, or emotional support for mom's recovery

Some fetal surgery centers are expanding their criteria to include more patients. For example, some allow a higher maternal BMI or abnormal fetal chromosome or echocardiogram results.

Other Considerations

Fetal surgery requires a big commitment from the whole family, but especially the mother. It may mean taking medical leave from work, temporarily relocating closer to the hospital, financial challenges due to these changes, finding someone to care for her during recovery, childcare for other children, and being on some level of bedrest for an extended time.

Outcomes

Benefits of fetal surgery

Improvement in hindbrain herniation

After fetal surgery, the brain may move to a more normal position, decreasing problems with **Chiari 2 malformation**. During the MOMS trial*, the fetal surgery group had fewer infants with evidence of **hindbrain herniation**, lower rates of moderate or severe herniation, and fewer Chiari decompression surgeries compared to the postnatal group.

Reduced need for shunting

If the **hindbrain herniation** improves, there is more room for cerebrospinal fluid to flow between the brain and spine and less chance of needing a shunt to help drain the fluid from the brain. Shunts are life-saving for those who need them, but they come with surgery risks and may require additional surgeries in the future. **The MOMS trial showed babies who underwent fetal repair were half as likely to need a shunt.**

Improved mobility outcomes

Covering the spinal cord prenatally stops progressive damage to the cord during pregnancy. Children who had prenatal surgery during the MOMS trial were twice as likely to walk independently (without equipment such as walkers and leg braces) at 30 months compared to the postnatal surgery group.

Risks of fetal surgery

Pre-term birth

The most common risk of operating on the baby and uterus during the pregnancy is **prematurity.** The earlier the baby is born, the more likely he or she is to experience complications, such as breathing difficulties, compromised immune system, hearing and vision problems, neurological issues such as brain bleeds, and other serious consequences. In rare cases, a baby may have to be delivered during or shortly after fetal surgery, sometimes too early to survive.

Tethered cord

Those who had fetal surgery during the MOMS trial were significantly more likely to need another surgery when they were older to release a tethered cord, which is scar tissue that attaches to the spinal cord and limits its movement.

The MOMS trial also showed *risks **for mothers*** who underwent fetal surgery. In addition to infection and other common risks of surgery, these include:

- **Placental abruption:** The placenta separates from the inner wall of the uterus, causing bleeding and potential blockage of the baby's oxygen and nutrients supply
- **Pre-term rupture of membranes**: "Water breaking" early
- **Postoperative pulmonary edema:** Buildup of fluid in the lungs
- **Uterine dehiscence:** Thinning or tearing of the incision on the uterus
- **Bleeding, need for blood transfusion**
- **Chorioamniotic Membrane Separation:** The layers of membranes in the uterus separate from each other
- Uterine rupture or dehiscence in **future pregnancies**

*** A seven-year (2003-2010) clinical research trial called Management of Myelomeningocele Study (MOMS) followed 183 women and their babies to compare the outcomes of fetal surgery for Spina Bifida versus surgery after birth.**

Types of Fetal Surgery

There are different types of fetal surgery, but most of the process is similar for each.

1. First, general anesthesia is administered to the mother, which also anesthetizes the baby for surgery.
2. The surgeon creates an incision across the mother's abdomen, then makes an incision in the uterus or puts small instruments through an intact uterus to access the baby's spine.
3. A neurosurgeon removes the sac (if there is one) over the myelomeningocele and closes the tissue and skin on the baby's back.
4. Then the incisions are closed.

Open hysterotomy

The MOMS trial used an "open" fetal surgery technique. A 6-8 cm incision is made in the uterus to open it for access to the baby's spine.

Because of the size and location of the incision in the uterus, the mother must commit to having a **c-section** to deliver the baby (and any future babies) to avoid uterine rupture during labor.

Fetoscopic surgery

A more minimally invasive procedure is now practiced at some centers. Instead of a larger opening in the uterus, a fetal surgeon performs the repair through two or three small incisions.

Outcomes are still being investigated, but smaller incisions may allow for **faster maternal recovery, reduced risk of premature birth and uterine rupture, and sometimes vaginal delivery.**

Recovery

After surgery, patients spend several days recovering in the hospital, then follow up weekly for ultrasounds and to check on the baby and mother.

Where the mother receives follow up care depends on the facility and often is decided on a case-by-case basis. **Many people travel for fetal surgery and must remain local to the fetal surgery center for the rest of the pregnancy.** If there is a children's hospital closer to home, some may be released to recover at home with local follow up care. Either way, mothers are usually on modified activity restrictions and require a "support person" to care for them at home and in case of emergencies.

Care After Birth

Babies with Spina Bifida should be delivered at or quickly moved to a hospital that has the experience and expertise to treat babies with Spina Bifida, whether that is at the same hospital as the fetal center or one closer to home. Babies who have undergone fetal surgery are typically delivered by 37 weeks. Most babies spend time in the NICU at first so they can be monitored by specialists.

Many of these specialists—neurosurgery, urology, orthopedics, and others—will continue to follow the baby for the next 18-21 years. Children with Spina Bifida need regular follow up care and testing for the rest of their lives. A list of Spina Bifida clinics may be found at ***spinabifidaassociation.org***. Visits are frequent at first and less so as children get older.

It is important that mothers also receive the postnatal care they need for their physical, social, and psychological well-being. If that care is provided in a different place than the fetal surgery hospital, comprehensive and careful coordination needs to be planned to assure the best care for mothers.

Postnatal Surgery for Spina Bifida

Though fetal surgery closure for Spina Bifida has become increasingly common in recent years, the other standard treatment for Spina Bifida is to close the opening on the back shortly after birth. Each family should be counseled to fully understand their options and make the best decision based on the medical status of the baby and mother as well as patient preference and family considerations.

Postnatal surgery is recommended or selected for a variety of reasons unique to each situation. For example:

- To avoid fetal surgery-related complications such as prematurity or because of previous premature deliveries
- Due to health conditions of the mother or child that make fetal surgery more risky
- Postnatal surgery does not usually require the same level of support and time off work as fetal surgery
- It is less physically taxing on the mother

Postnatal surgery is always recommended in multiples pregnancies.

Pregnancy

Once you make the postnatal surgery decision, your baby's growth and condition will be monitored with routine ultrasounds throughout the pregnancy. Specialists will observe the baby's feet to see if they are clubbed, watch the ventricles in the brain for excess fluid, monitor the baby's overall growth, and perform other tests as needed.

Delivery

Babies with Spina Bifida should be delivered at a hospital with, or connected to, an appropriate Neonatal Intensive Care Unit (NICU) to limit mom's and baby's separation and simplify communication between their medical teams.

The delivery will be planned near your due date to ensure your baby will be as strong and healthy as possible for surgery. It is helpful to plan the delivery so that key specialists will be available.

Both vaginal and cesarean deliveries are considered safe for babies with Spina Bifida, but your particular case may be better suited for one or the other. Whenever vaginal delivery is safe for the baby, it will usually allow mom an easier recovery.

Considerations for a planned c-section may include previous c-section deliveries, very large ventricles that have increased the baby's head size, a particularly large sac over the opening that may be damaged during delivery, or preference.

After birth

Babies are handled very carefully to protect the exposed spinal cord. If there is an opening on the back, it will be covered by a sterile dressing, and infants are often positioned on their sides or bellies. Your baby will be transferred shortly to the NICU, where assessment and care will be provided by his or her medical team. For example, a neurosurgeon may evaluate the baby soon after birth and order tests to see the spinal cord and brain in preparation for surgery to close the open lesion.

Surgery

Closure surgery is usually done within 24-48 hours after birth to close the opening on the back. Surgery does not "fix" any damage that has already occurred, but it helps prevent infection and further injury to the spinal cord.

Your baby will undergo general anesthesia. A neurosurgeon will remove the sac (if there is one), place the spinal cord in the correct position, and then close the dura (the covering over the spinal canal), muscles, and skin over the opening. Sometimes plastic surgeons help if there is an especially large opening that is more difficult to close.

Some risks for postnatal closure of myelomeningocele are the same as any surgery: infection, bleeding, breathing problems, and reactions to medicines. Additional risks for this particular surgery include:

- Fluid buildup and pressure in the brain after the lesion on the back is closed
- Infection or inflammation of the spinal cord
- Paralysis, weakness, or sensation changes due to loss of nerve function

After surgery

- Your baby will return to the NICU to recover.
- He or she may need to lie flat (head level with back, not inclined) on his or her belly to help the wound heal and may receive antibiotics to prevent infection.
- Neurosurgery will keep a close watch on the baby's spine and brain after surgery to see if fluid begins to build up in the brain after the lesion on the back is closed.
- If so, the baby may receive another surgery for a shunt or ETV (endoscopic third ventriculostomy) to relieve pressure and prevent damage to the brain.

Families can expect the baby to spend about 2 weeks in the hospital after surgery, but the length of stay can be shorter or longer based on the baby's individual needs.

Continued Care

Several specialists—neurosurgery, urology, orthopedics, and others—will follow your baby for the next 18 years or more. For the best outcomes, children with Spina Bifida need regular follow up care and testing for the rest of their lives. A list of Spina Bifida clinics may be found at ***spinabifidaassociation.org***. Visits are frequent at first and usually less so as children get older.

It is important that mothers also receive the postnatal care they need for their physical, social, and psychological well-being. If that care is provided in a different place than the hospital where they deliver, comprehensive and careful coordination needs to be planned to assure the best care for mothers.

Adoption for Babies with Spina Bifida

Some families choose to make an adoption plan for their baby with Spina Bifida. Parents may explore adoption as a secure and permanent option for their baby either during the pregnancy or after the baby is born.

Those considering adoption can ask their providers for referrals to local adoption agencies or attorneys that specialize in "special needs" adoptions. These agencies offer services such as:

- Counseling to birth parents throughout the process
- Financial assistance in some cases
- Screening and helping select adoptive parents
- Helping both parties determine what type of relationship (level of openness) they want going forward

Closed Adoption

Gives the most privacy by limiting the information shared about each other

Open Adoption

Allows the families to meet each other and continue communication as the child grows up

Kinship Adoption

Grants parental rights to a relative of one of the birth parents

Next Steps

As you weigh all of your options, connecting with an agency can help you determine whether relinquishing your parental rights is what is best for you and your baby. Connecting with other birth parents or birth parent support groups can also help you understand the process, feel less alone, and provide support during this difficult time.

Resources

Search for agencies at:

adoptionagencies.com and support groups and other resources from the National Council for Adoption at ***adoptioncouncil.com***

Parents who choose to make an adoption plan must also decide whether to opt for fetal surgery or postnatal surgery to close the opening in the baby's back. Please see the **Fetal Surgery for Spina Bifida** and **Postnatal Surgery for Spina Bifida** information sheets for more information.

Ending a Pregnancy Affected by Spina Bifida

You may also be offered the option of terminating the pregnancy (also known as abortion). Termination for Medical Reasons (TFMR) is a highly personal decision, and only you can determine what is best for you and your family.

Termination laws vary widely by state and are time sensitive with regard to how far along you are in your pregnancy. Your provider can help you understand any restrictions and connect you with an appropriate termination provider such as a medical center or Planned Parenthood to help you learn more about whether this is an option for you.

Pregnancy loss, regardless of the cause, can cause a range of strong emotions. Your medical provider can refer you to an appropriate counselor, therapist, or support group to help you cope.

Termination providers can be found at:

Abortion Finder: *abortionfinder.org*

Abortion laws by state can be found at:

The Center for Reproductive Rights: *reproductiverights.org*

There are a number of online support groups, such as:

TFMR Mamas: *tfmrmamas.com*

The TFMR Doula: *thetfmrdoula.com*

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Our mission is to build a better and brighter future for all those impacted by Spina Bifida.

Additional information

For more information and lifelong support, connect with the Spina Bifida Association at:

spinabifidaassociation.org, or by contacting the SBA National Resource Center at **(800) 621-3141, ext. 800** or *sbaa@sbaa.org*.

If you're an expectant parent, scan for more information and resources just for you.

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