American Pediatric Surgical Nurses Association Inc.
Safety and Excellence in the Surgical Care of Children

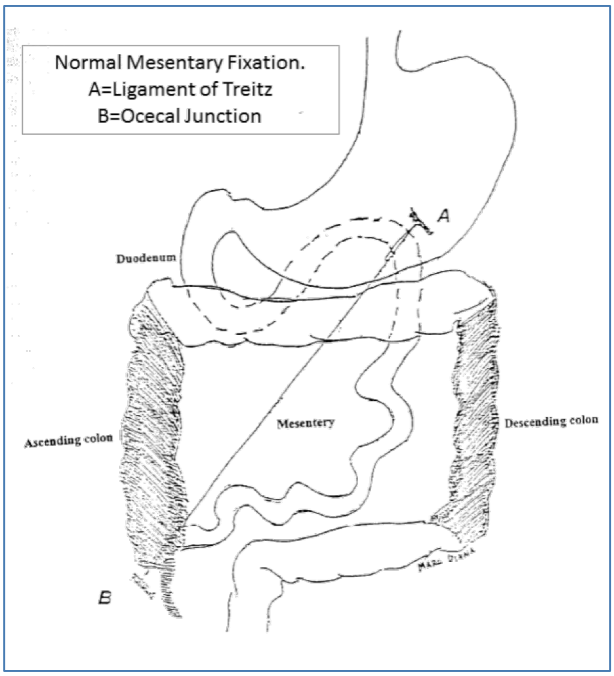
PATIENT AND FAMILY INFORMATION SHEET

Malrotation and Volvulus

What is malrotation and volvulus?

Malrotation is a serious health problem that happens before birth, when a baby is growing and developing inside the mother. During normal development, the small and large intestines grow, make a turn and attach inside the belly to prevent moving around. This is called rotation and keeps the intestine and blood flow in a safe arrangement. If the intestine does not make the full turn and attach this way, it is called malrotatation.

Malrotation is not safe, because the small intestine can move and possibly twist on itself, squeezing the vessels and stopping blood flow. This is called a volvulus, a very dangerous condition that can cause the intestine to be harmed and possibly die. In malrotation, it is also possible to have abnormal bands of tissue that attach from the belly to the intestines. This can press on the small intestine and cause a blockage.



A baby can have malrotation without having a volvulus. This is dangerous because of the small chance of developing a volvulus at any time. Although malrotation develops before birth, it is usually found during the first year, and most often during the first month of life. Some babies grow into children and adults with little or no symptoms. Once malrotation is found, it is important to know this may develop into a volvulus. If this happens, your baby/child may become quite ill very quickly. If your child has malrotation with or without the signs listed below, the surgeon will talk with you about whether or not an operation is needed.

The reason a baby develops a malrotation is not known.

How do I know if my child has malrotation and/or volvulus?

Here are some of the signs your baby may have:

- Belly pain
- Fussiness, crying
- Difficulty passing bowel movements (pooping)
- Slow growth
- Throwing up liquid that is yellow or green in color. This is called bile and can be a very serious sign.
- Not feeding well or refusing feedings can be a serious and concerning sign
- Swollen belly that may be painful when touched (serious sign)

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How do I know if my child has malrotation and/or volvulus?

Here are some of the signs your baby may have:

- Blood in the stool (serious sign)
- Much less active that usual, weak or not responding to usual activity (serious sign)

If your baby is throwing up bile it is important that you notify your baby's provider (Doctor, Nurse Practitioner or Physician Assistant) immediately or if after hours go to the nearest emergency room. This can be a sign of volvulus which is an emergency.

How is malrotation and volvulus treated?

- Malrotation cannot be treated with medication and will not go away on it's own.
- The only cure for malrotation and/or volvulus is an operation.
- An operation for malrotation is not an emergency and can be scheduled in advance.
- An operation for volvulus is an emergency and must be done quickly after discovered. An operation for volvulus is life-saving.

What happens before the operation?

If malrotation or volvulus is suspected, the provider will order tests to see if the intestine is in the normal position, and if the intestine is twisted or blocked. These tests may be:

- **Special X-ray studies:**
  - **Abdominal X-ray:** usually taken first, may show a blockage of the intestine.
  - **Upper Gastrointestinal study (UGI)** including the first part of the intestine, is the test of choice if malrotation is suspected. The baby is given a fluid called contrast (this can be seen on the UGI study as it flows into and fills the intestine). This is usually given by a tube going from the nose to the stomach since most babies will not drink contrast. Many X-rays will be taken to follow the contrast as it flows from the stomach into the small intestine. This can show whether the positioning of the intestine is normal or malrotated.
  - If a volvulus is suspected, this is an emergency, and your provider may order a test called a **contrast enema**. This test is done by placing a tube in the bottom and allowing contrast to fill the intestine. This will show if a volvulus if present.
  - **Abdominal Ultrasound or a special X-ray called a CT or CAT Scan** (Computed Tomography Scan) to check for other causes of throwing up and belly pain.
- **Blood tests:**
  - Electrolytes (BMP): If the baby is throwing up, blood tests will be sent to check electrolytes (minerals) in the blood.
  - Complete Blood (CBC) to look for signs of infection and to check for anemia (a low number of red blood cells).
  - Type and Screen: to prepare for possible blood transfusion, if the red blood cell count is low) and an operation is planned.

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What happens before the operation?

- Other treatment:
  - If your baby is throwing up, a tube called a nasogastric (NG) drainage tube may be placed through the nose and into the stomach to drain the stomach and upper intestine.
  - Your baby will be given intravenous (IV) fluids to replace the fluid that is lost from throwing up and not drinking.
  - IV medicine will be given. This might include antibiotics to fight infection.
  - IV nutrition may be given if your child cannot eat normally for some time.

What happens during the operation?

The operation can be safely done in one of two ways:

- **Open operation:** The operation is done through a horizontal (side to side) cut or incision in the right upper part of the belly or through a vertical (up and down) cut in the middle of the belly.
- **Laparoscopy:** A few small cuts will be made in the belly. A video camera is placed through one of the cuts. The operation is done using small tools placed through the other cuts.

Malrotation without volvulus

- If your baby has a malrotation, an operation may be recommended. This is not an emergency. In this operation the blood supply and intestine are arranged in such a way that the blood supply is spread our widely, bands of tissue that hold the intestine in an abnormal position are cut and the small and large intestine are arranged in such a way that a twist of the intestine and blood supply that can cause a volvulus is unlikely to happen.
- When there is malrotation, the appendix can be found in an abnormal position, not in the right lower belly where it is usually found. Should your baby ever have appendicitis, the diagnosis may be hard to make. In other words, when the appendix is not found in the usual place, the diagnosis may be missed or delayed. Because of this, the appendix may be removed during the operation for malrotation. Please ask the surgeon if the appendix was removed and save this information in your baby's health record. This information is important for your baby to know when he/she becomes an adult and takes care of their own health.
- If your baby has malrotation, an operation may be recommended. This is not an emergency. In this operation, the blood supply and intestine are arranged in such a way that the blood supply is spread out widely. To prevent a volvulus., bands of tissue that hold the intestine in an abnormal position are cut; the small and large intestine are then arranged to prevent a twist of the intestine and blood supply.

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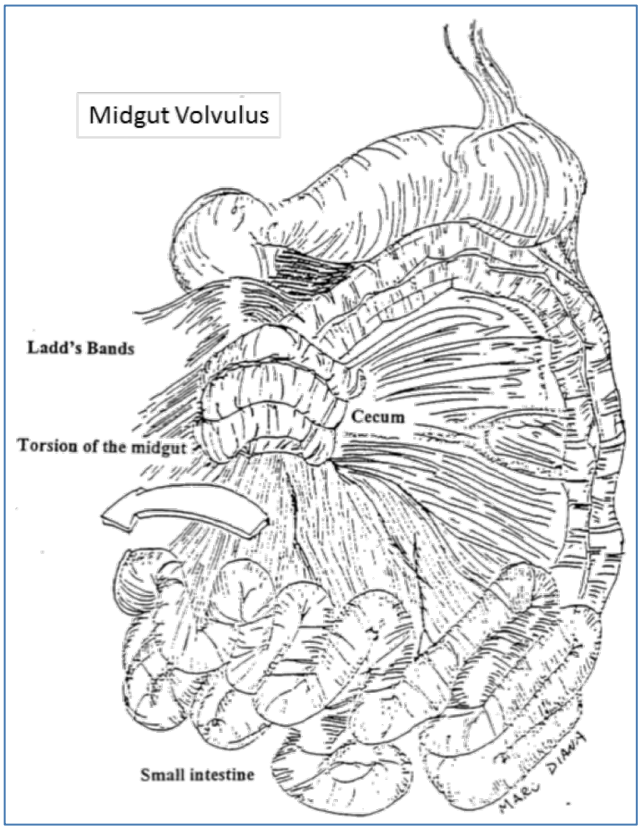
Malrotation and Volvulus

Malrotation with volvulus

- This is an emergency. Once your baby's surgical team has found there is a volvulus, an operation must be done immediately. There is no other way to save the small intestine from harm and dying from lack of blood flow.
- During the operation the intestine is untwisted to restart blood flow. This may be all that is needed to help the intestine recover.
- If the intestine is harmed and not able to recover the damaged section will need to be removed.
- If there is much intestine harmed the intestine may be placed in a clear plastic bag called a silo to be watched for a few days to see blood flow is restored. The baby will then go back for an operation to close the belly and, if needed, remove any bowel that has died from lack of blood flow.
- The surgeon may take the baby back to the operating room for a second operation in a few days, to check and see if the intestine has recovered. Intestine that has died will need to be removed.
- If intestine is removed the remaining healthy intestine will be sewn together.



What happens during the operation?

Malrotation with volvulus

- If there is a lot of intestine that must be removed, the baby may need an ostomy. An ostomy is made by bringing intestine through an opening on the outside of the belly where stool (poop) can drain into a bag called a pouch. Based on how much intestine is removed, the ostomy may be temporary (lasting for a few months) and reversed with another operation, or in rare cases, may be long term (lasting years) or be permanent.
- In this operation, the blood supply and intestine are arranged in such a way that the blood supply is spread out widely. Bands of tissue that hold the intestine in a normal position are cut, and the small and large intestine arranged in such a way that a twist of the intestine is unlikely to cause a volvulus.
- In either situation, if the decreased blood flow affects a large section of intestine, the baby may have a long recovery or may not survive. For babies that do survive, a loss of a large portion of the small intestine can lead to a condition called Short Bowel Syndrome. This condition requires very specialized care, supplies, equipment and caregiver training.

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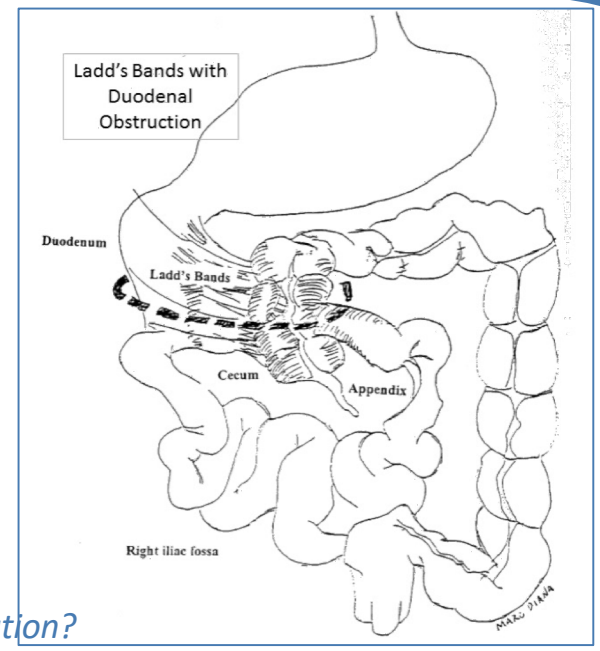
What happens during the operation?

Malrotation with volvulus

- After an operation for malrotation, there is still a very small chance the symptoms and malrotation can occur again.
- After an operation for malrotation, there can be formation of scar tissue that can compress the intestine and cause an obstruction. The signs of obstruction are vomiting that does not stop and turns green. This can happen at any time during the baby's life and cannot be predicted in advance. This information is important for your baby to know when he/she becomes an adult.



What happens after an operation?

When can I be with my baby again after the operation?

- As soon as your baby wakes up after the operation and in in the recovery area, you will be called so you can be with your baby as soon as possible once he or she is settled.
- Visiting hours and rooming in will be determined by the hospital in which you and your baby are staying.

When can my baby eat again?

- Your doctor will tell you when your baby may start feeding again. Most often it will be when the Intestine starts working (passing gas and poop and no more throwing up).
- If your baby has a drainage tube in their nose it will need to be removed first before food can be given.
- If feedings are delayed for a long period of time, nutrition may be given by IV.
- When babies have been very ill, feedings may be given by a tube called a nasogastric (NG) tube. The tube may be placed through the nose and into the stomach temporarily, until your baby is strong enough to eat by mouth.

Will my baby have any pain?

Your baby will have belly pain after the operation. Pain medicine may be given through the IV or by mouth (if the baby can drink) in order to keep your baby as comfortable as possible.

When can my baby go home?

- This depends on what happened before, during the operation, and how sick your baby has been. Babies who have a non-emergent operation will recover and go home quickly. Those who are very ill and undergo an emergent operation will take longer to recover, and often have to stay in the Intensive Care Unit. These babies will need to stay in the hospital longer.
- When your baby is feeding more normally, he/she will be discharged home.

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When can my baby go home?

- There is no fever or signs of an infection.
- Pain is well-controlled with medicines taken by mouth.
- The cuts are healing well
- If your baby has an ostomy, you will need to learn to care for this before going home. Supplies for home will be arranged by the surgical team or hospital discharge planner.
- If your baby was very ill, there may be additional care and procedures to learn before going home. This includes babies who have Short Bowel Syndrome.

How do I care for my baby at home?

- Keep the dressing/cut clean and dry for the time specified by the surgical team.
- Bathing (school and sports if age appropriate) to resume per the surgical team instructions
- Your baby/child's activity will return to normal with time.
- You baby/child's diet will return to normal. Changes may be made if there is an ostomy or Short Bowel Syndrome.
- The pediatric surgery team will give you more information specific to your baby's needs before you leave the hospital.
- A visiting nurse may be requested to help with education at home.
- The surgical team will review signs of an intestinal obstruction or a volvulus with you. I
- It is a good idea to call your baby's provider to ask if an appointment is needed once you are home and your baby is recovering.

When should I call the office?

- *If your baby has any of the following, please call our office:*
- Fever more than 100.5 F or 38.0 C.
- Pain that does not go away with over the counter pain medicine.
- The cut that looks red, swollen, or has liquid coming from it.
- Not eating well or throwing up feedings or bile.
- If there is an ostomy, the stoma has a change in color or appearance or is not draining stool.
- Any questions that you may have.

Your child will need to follow up with the surgeon. You will receive specific instructions for follow up when your child is discharged.

Please don't hesitate to call our office if you have any problems or concerns.

Surgeon: _____
Nurse Practitioners: _____
Phone Number (daytime): _____
Phone Number (after hours): _____
Social Worker: _____

Thank you for allowing us to care for your child.