

PATIENT AND FAMILY INFORMATION SHEET

Omphalocele

What is an omphalocele ?

An omphalocele happens when there is an opening in the wall of the belly which the bowel and possibly other organs in the belly push through to the outside of the baby's body. The organs are covered by a thin sac where you can also see the umbilical cord (Figures 1 and 2).

- While your baby was developing inside, the wall of the belly did not close correctly.
- Omphaloceles can be small or large.
- Other birth defects can be found in babies who have omphaloceles.



Figure 1



Figure 2

How do I know if my baby has an omphalocele?

You may have been told your baby has an omphalocele before birth. The following tests may have been done::

- A blood test called a "maternal serum alpha-fetoprotein" or AFP. This test may have been higher than normal. This test is not just for an omphalocele. It may be high for other reasons.
- An ultrasound that showed the bowel and organs were in a sac outside of your baby's body.
- A test of the "water" around the baby (amniocentesis).
- An ultrasound of the baby's heart (fetal echocardiogram).

How is an omphalocele treated?

Treatment will depend on the size of the opening of the baby's belly wall and the baby's overall health at the time of birth. There are different ways to treat an omphalocele:

- If your baby has a small sized opening (less than $\frac{3}{4}$ inch or 2 cm), the bowel and organs will be gently put back into the belly and the opening will be stitched closed (primary repair).
- If your baby has a medium sized opening (less than 2 inches or 5 cm), the bowel and organs will be put into a plastic bag called a silo. Every day, a small amount of the bowel and organs will be gently pushed back into the belly. This can take many days. Once all of the bowel and organs are back in the belly, the opening will be stitched closed (staged repair).
- If your baby has a very large opening (larger than 4 inches or 10 cm), it is difficult for the bowel and organs to fit back into the belly. In this case, the sac covering the organs may be painted with a special solution or covered with a special dressing. After some time, skin will grow over the large opening. Eventually, this will leave a smaller opening in the belly wall (hernia) which can be closed in the operating room later.

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Pictures of a giant omphalocele

What happens after surgery?

After omphalocele repair, it will take time for the bowel and organs to get used to being back inside of the belly.

- During that time your baby will have an intravenous (IV) line to get liquid nutrition and medications.
- Your baby may not be able to eat for some time. When the bowels begin to work, feedings will be started very slowly. Each baby is different and you will need to be patient until your baby is ready to eat.
- The baby might have some setbacks and the feedings may need to stop for some time. This will give the bowel time to rest and heal.
- Sometimes, another surgery is needed.

When can we go home?

- The length of stay in the hospital after omphalocele repair varies, depending on a variety of things:
 - The size of the opening
 - How the omphalocele was treated
 - The overall health of your baby
- Before going home, your baby will need to:
 - Breathe on their own (with or without supplemental oxygen)
 - Be able to tolerate their feedings
 - Maintaining their own temperature
 - Gain weight
- Another important milestone is making sure that you and any other caretakers are ready to take care of your baby at home. Support is available to help you and others learn to care for your baby.



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How do I care for my baby at home?

- Every baby has different needs. We will teach you what you will need to know to take care of your baby at home.
- It is important to keep all of the appointments with the surgeon, pediatrician, and other specialists that are needed for your baby.
- It is helpful to write down everything your baby has gone through so you can give this information to the health care providers caring for your baby.
 - You can ask your team to give you copies of important papers (example: operation reports, discharge summaries, and medicine lists).
 - Keep these papers in a safe place so you and your child will always have them.
 - You should take these papers with you when you see a new health care provider or go to the emergency room.
 - Your hospital team can help you get this information together.

When should I call the office?

If your baby experiences any of the following, please call our office:

- **Vomiting. If the vomit looks bright yellow or green, this is an EMERGENCY! Call the surgeons office right away. If you do not reach someone, go to the closest emergency room!**
- Fever (Temperature more than 100.4°F [38.0°C])
- Signs of infection of the belly:
 - Redness, swelling, yellow drainage
- Call for any questions or concerns that you may have. We are always ready to help you.

Your child will need to follow up with the surgeon.

You will receive specific instructions for follow up when your child is discharged home.

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

Surgical provider: _____

Office Number: _____

After hours number, if applicable: _____

Thank you for allowing us to care for your child.