

Omphalocele

In normal development before birth, the intestines are formed in a sac around the umbilical cord, and then move into the baby's body. The abdominal muscles close and skin develops over the muscles. If the intestines stay in the sac (and do not move into the baby's body) it is called an omphalocele (ohm FAL oh seal). When a baby is born with this defect, the umbilical cord sac usually covers the intestines. Sometimes the sac breaks and the intestines lie completely outside the baby's body.

Often, a baby with omphalocele has an abdominal space that is small compared to overall body size. A baby with omphalocele may have other birth defects such as heart problems that complicate treatment.

Treatment of Omphalocele

- If the defect is small, surgery may be done right away to put the abdominal contents inside the abdomen. The muscle and skin will also be closed. This is called a primary closure.
- If the skin cannot cover the intestines, the sac may be coated with an antibiotic to prevent infection. The edges of the skin will gradually grow over the sac. This can take several weeks. Then the baby goes home and comes back when older for the repair that brings the abdominal muscles together.
- Your baby will receive antibiotics and nutrients (such as carbohydrates, water, electrolytes, protein and fats) through an IV. The child will not be fed into the stomach until quite a while after surgery, so that the intestines have time to heal. A tube that goes from the nose or mouth into the stomach (called a NasoGastric or OroGastric tube, or NG or OG tube) will help keep the stomach empty.
- Even though your baby cannot be fed by mouth during this time, you may give your baby a pacifier. This helps your baby develop skills for sucking (**Picture 1**).



Picture 1 A pacifier helps satisfy your baby's need for sucking.

After the Surgery

- Your baby may be on a ventilator (a machine that helps with breathing) until he or she can breathe well without help.
- At first all of your baby's nutrients will be given through the IV. An NG or OG (nose or mouth) tube will be in place until your baby is ready to be fed by mouth or feeding tube.
- When your baby can take liquids, he or she may be fed by bottle or through a feeding tube. Feedings will be started slowly until your baby's body can handle more. This is often a slow process.
- Before your baby can go home, he or she must be eating enough formula or breast milk to gain weight normally. The doctors may have to try several formulas to find the one that is best for your child. This can be frustrating for you and your family.
- How long a baby will stay in the hospital will depend on many things, including the size and severity of the defect.
- An occupational therapist (OT) or physical therapist (PT) may work with you and your baby during the hospital stay.
- Because babies with omphalocele may have other defects, tests will be done to check the baby's heart, kidneys and brain.
- Your baby's hearing will be checked before he or she goes home.

Follow-up Appointments

- You will have a follow-up appointment with the surgeon, usually about 2 weeks after going home. A case manager will arrange this appointment for you.
- You will also need to make appointments with your child's primary care doctor for regular follow-up care.

Long Term Outlook

If there are no other problems, most babies with omphalocele survive. Even with serious problems, over 70% of infants survive.

Parenting

- All babies need to be held and touched. The nurses will help you do this and soon you will feel comfortable holding your child.
- You may also bathe your baby and change the diapers. Save them for the nurse to check.
- You may bring toys, music boxes, or other items from home to enhance your baby's development.

This is a stressful time for you, your baby, family and friends. Your doctor, nurses and others are here to help you. If you have any questions, be sure to ask your doctor or nurse.