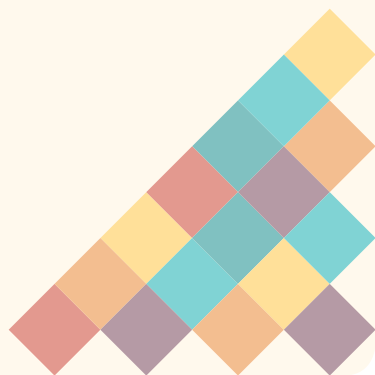


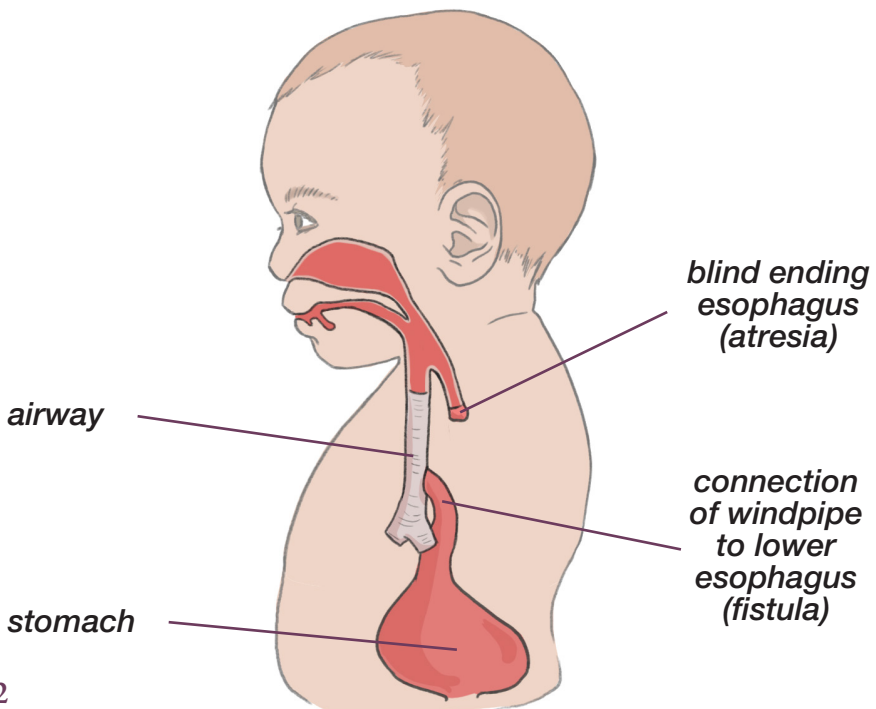
Neonatal Intensive
Care Unit (NICU)

Having a Baby with Esophageal Atresia and Tracheoesophageal Fistula



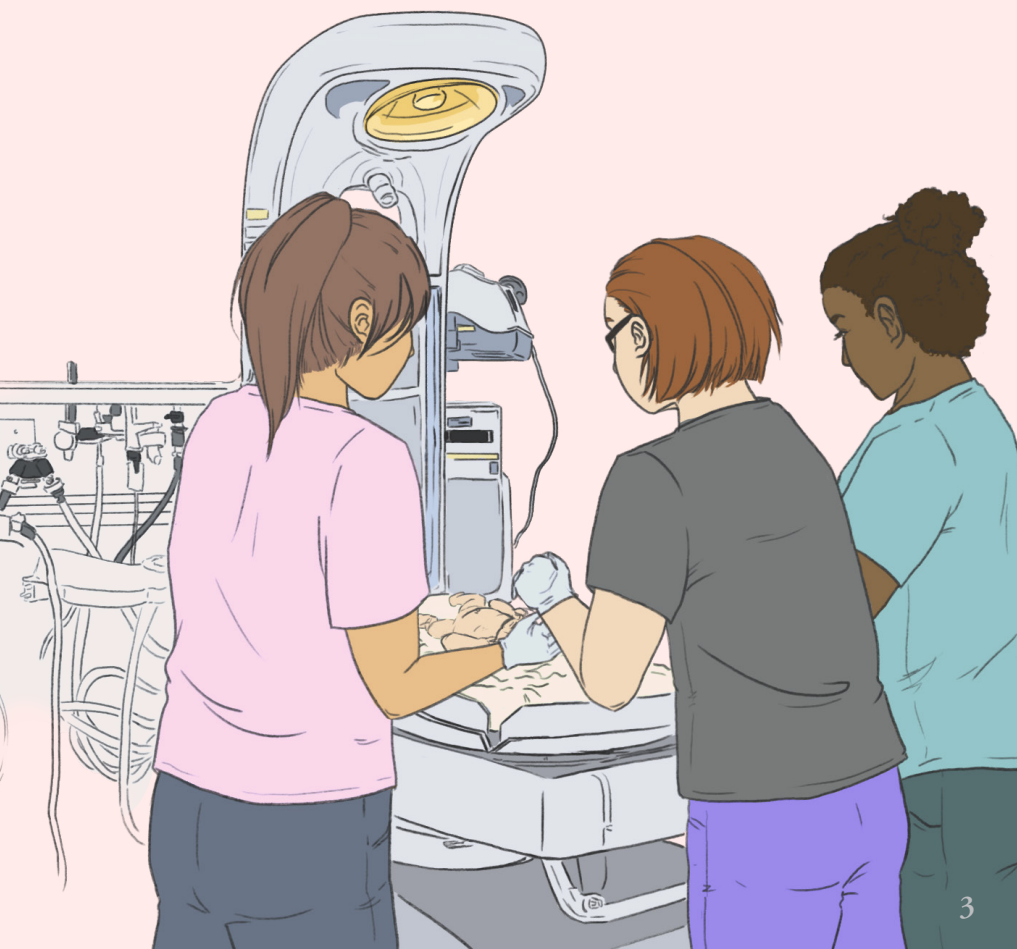
What are Esophageal Atresia and Tracheoesophageal Fistula?

Esophageal atresia (EA) is a condition affecting a newborn child in which a discontinuity (atresia) exists in the food pipe (esophagus) resulting in no direct connection from the mouth to the stomach from early on in pregnancy. In comparison, tracheoesophageal fistula (TEF) is an abnormal connection between the windpipe (trachea) and the esophagus. Several variations exist with the most common being esophageal atresia with a distal tracheoesophageal fistula (EA/TEF) (type C). The condition itself does not seem to cause a baby any pain, and the most common type C can usually be repaired by surgery after birth. Sometimes, EA/TEF may be associated with other medical issues or genetic conditions. Many babies with EA/TEF grow up to be healthy adults without significant long-term medical issues.



Giving Birth to a Baby with EA/TEF

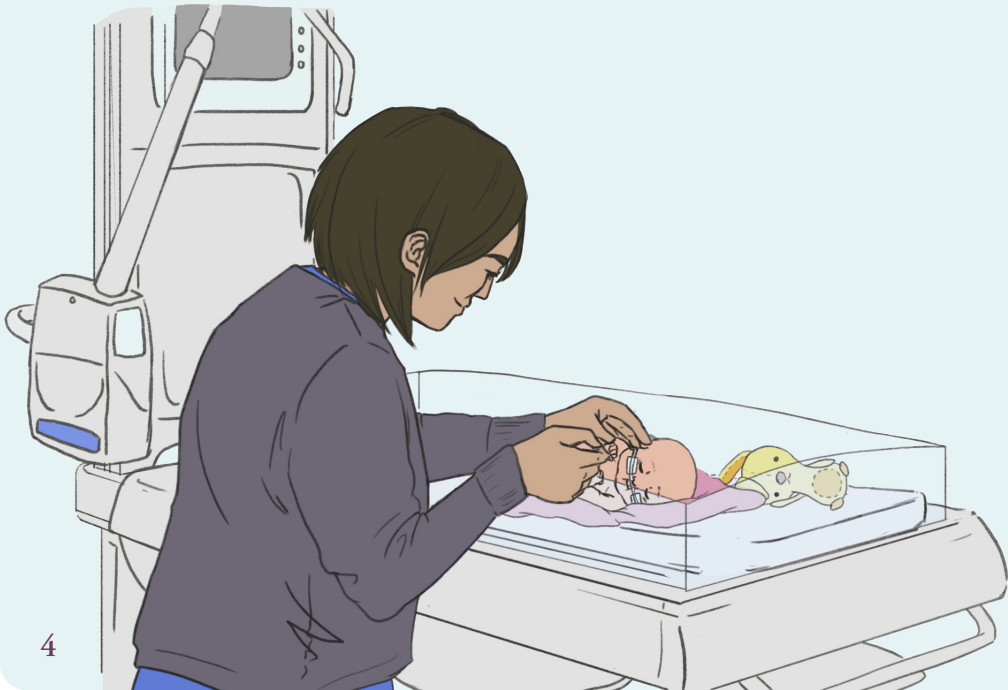
Generally a baby with EA/TEF can be born vaginally. Some babies with EA/TEF need to be born by caesarean section generally for the same reasons as babies born without EA/TEF. For example, if the baby is not in a head-down position, a caesarean section may be most appropriate. Since babies with EA/TEF require special care after birth, families expecting a baby with EA/TEF are recommended to relocate to Edmonton approximately 3 weeks before their due date.



Once the Baby is Born

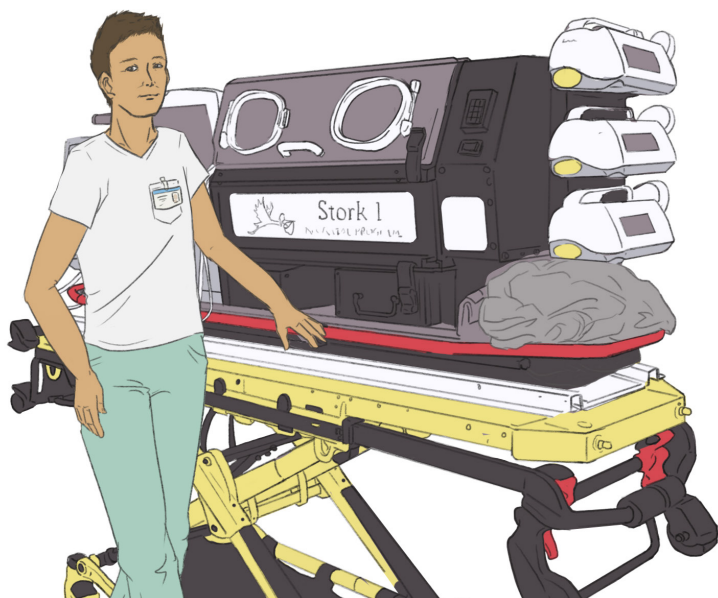
Babies with EA/TEF need special care as soon as they are born. A team of newborn specialists is at the birth. A soft, plastic (Replogle) tube is inserted through the mouth to the blind ending of the upper esophagus to suction. Since saliva cannot be swallowed, this tube prevents the secretions from getting into the lung. We start intravenous (IV) lines to give medications and nutrition. Babies with EA/TEF are at increased risk of needing help to breathe and some may require assistance of a breathing machine.

The newborn team is experienced in helping babies with EA/TEF. It is important for parents to spend time with their babies, and if the baby is stable, we try to help parents see and touch their baby before they are moved to the Neonatal Intensive Care Unit (NICU). Parents should let the medical team know of any special wishes they have for the delivery so we can do our best to accommodate these requests when possible.



Transfer to the Neonatal Intensive Care Unit

A specialized transport team brings babies with EA/TEF to the NICU at the University of Alberta Hospital. The team uses an incubator that looks like a plastic box with monitors and machines fastened to an ambulance stretcher. This transport incubator keeps babies warm, secure, and protected as we keep providing medical treatments in the ambulance. Usually, it is a calm, slow ambulance ride to the University of Alberta Hospital.



Mothers have to remain at the birth hospital until they have recovered. Other family members can follow the ambulance by car and come directly to the NICU. Typically mothers delivering vaginally may be discharged within a day of delivery. Mothers delivering by caesarean section usually require three to five days in the hospital, however they may receive passes to visit the NICU earlier depending on their recovery. Parents are essential to their baby's care in the NICU and are welcome at anytime of the day or night.

Treatment of EA/TEF

The University of Alberta NICU team, including the pediatric surgeon, examines babies with EA/TEF after they arrive. Specialized IVs are inserted through the belly button (umbilical lines) or elsewhere on the body through a vein in an arm, leg, or scalp (peripherally inserted central catheter, PICC line). Tests that need to be done prior to surgery include chest x-rays and ultrasound of the heart. We also routinely do head and abdomen ultrasounds and genetic testing to look for additional medical issues.

If there are no complicating conditions, surgery is typically performed within a few days of admission. The baby will return from the operating room with a surgical wound typically around the left side of their chest.



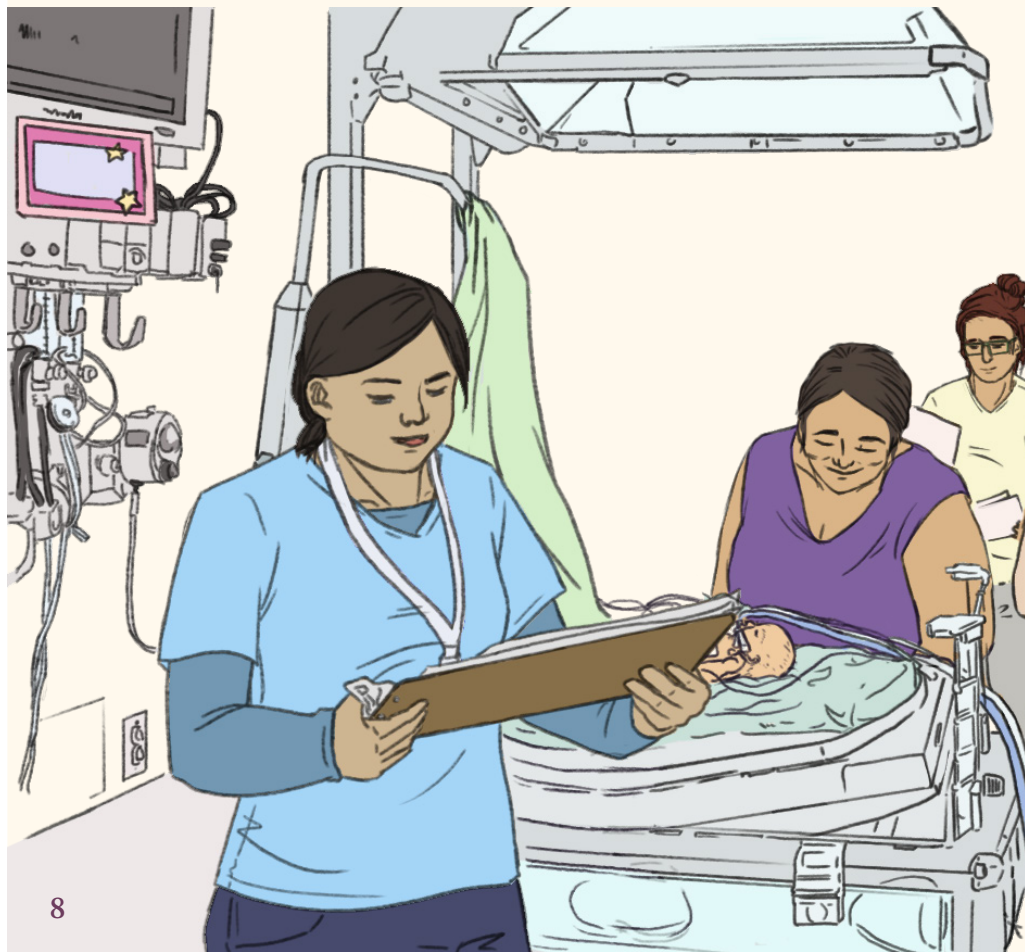
For most cases of EA/TEF, a single surgery is required to reconnect the esophagus and remove the fistula (connection to the trachea). For babies where the gap in the esophagus is too long to permit a single surgery repair, or if multiple fistulas exist, other surgical options exist. After surgery, babies return to the NICU with a breathing tube in place, a plastic tube inserted through the nose (called a nasogastric or NG tube) to support the reconnection of the esophagus. A thicker, firmer tube may also be inserted into the chest to drain fluid (chest tube).

Medical therapies are required to take care of babies with EA/TEF before and after surgery. Since babies with EA/TEF are unable to eat both before and sometime after surgery, we provide nutrition through an IV. This is called total parenteral nutrition, or TPN and includes everything the baby needs to grow: sugar, protein, and fat. Although we do not think that EA/TEF itself causes babies pain, pain and sedation medications are sometimes given before and always after surgery to keep the baby comfortable.

The recovery period involves medications for pain control, slowly decreasing breathing support from machines, and providing nutrition support. Often we are able to remove the breathing tube within a few days of surgery. A special x-ray called an esophagram is completed one week after surgery to make sure there is no leak in the esophagus repair before removing the chest tube. We start feeds slowly after surgery either through the NG tube, or by mouth if the special x-ray shows no leak in the esophagus. It may take a week or longer after surgery before feeds may be started. The first feed can be pumped breast milk. Once the baby tolerates these feeds then we help mothers and babies as they begin breast or bottle-feeding. Figuring out breast or bottle-feeding can take a few to many weeks after the surgery. The nurses will help mothers to start pumping breast milk as soon as possible after delivery to establish and maintain their milk supply. A lactation consultant is available to support parents.

Being a Parent in the NICU

Being a parent in the NICU can be an overwhelming experience. We recognize that it can be alarming for a parent to see their child connected to medical monitors, intravenous lines, and other medical equipment. We understand that seeing all of this might make bonding between parents and their children harder. It is important for parents to touch, talk, and be present for their babies even though it might not be possible for them to hold them out of the bed. Your team can suggest alternative methods to cradle or hold your baby in the bed. As soon as we can, we help parents hold their babies. As a NICU team, we support families and value their voices.



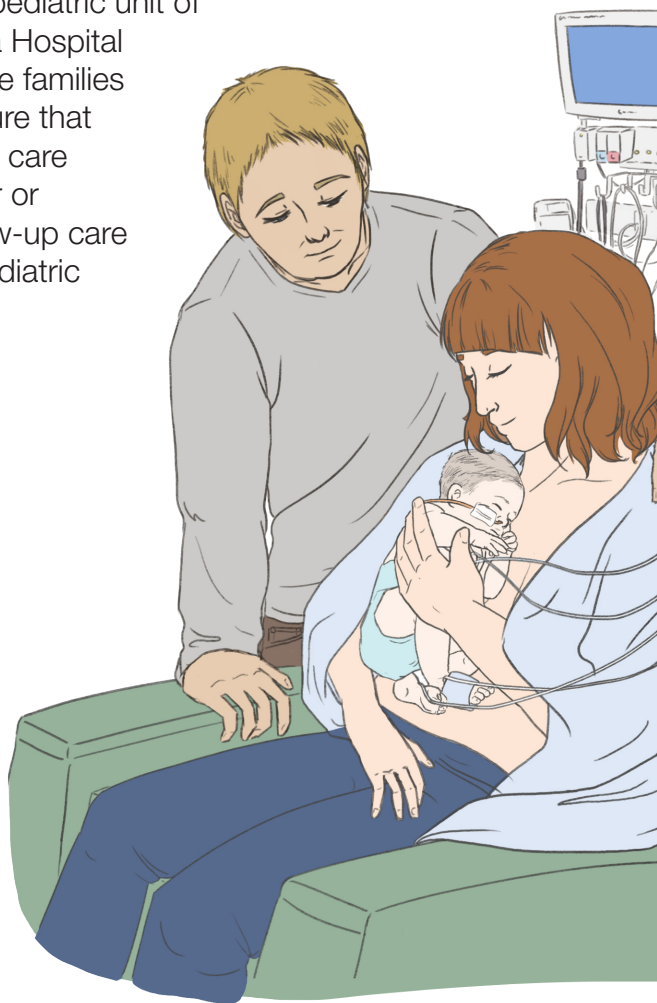
There will always be nurses and respiratory therapists to make sure a baby receives the care they need. The medical team can help explain the medical equipment and procedures. Every morning, a whole team of doctor, nurses, and other practitioners see the babies and decide about care. We call these “morning rounds” and parents are encouraged to be there to ask questions and express concerns. As well, every family meets a social worker who will provide support and help access resources.

Parents are welcome to bring personal and comforting items for their baby such as photos, small stuffies, blankets and clothing – best if the clothing is not knitted or woven as these could get caught on some of the supports and equipment like IV’s. Diapers and other supplies needed for daily care are provided. Family and friends can come visit the baby. There is a reception on the unit for safety and security.



Preparing for a Hospital Stay

We suggest that parents prepare for a hospital stay of 1 to 2 months after birth. Different issues might make the hospital stay longer, such as taking time to tolerate feeds, narrowing or scarring (strictures) of the food pipe (esophagus) or wind pipe (trachea), leaks of the repair site, or floppiness of the airways (tracheomalacia and/or bronchomalacia). Many infants also have issues of food coming back up (reflux) which requires anti-reflux medications. We talk about everything with parents as soon as we anticipate or notice a complication happening. Often, the baby will be moved to another Edmonton-area NICU or to a general pediatric unit of the Hospital of Alberta Hospital during recovery. Before families go home, we make sure that babies have a primary care provider (family doctor or pediatrician) and follow-up care arranged with their pediatric surgeon.



Notes



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