A Guardian's Guide to

Esophageal Atresia

From the NICU to early childhood and beyond…

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Congratulations on the birth of your new baby!

Esophageal atresia (EA) is a birth defect, in which a child is born without a continuous connection between the esophagus (food pipe) and stomach. In many cases there is also an abnormal connection between the esophagus and windpipe (trachea); this is called tracheoesophageal fistula (TEF).

While most children have surgeries to reconnect their esophagus and stomach very soon after birth, it is often difficult to restore full function to this part of the digestive tract. Children with EA/TEF may experience difficulty swallowing, stomach contents refluxing into the esophagus, and recurrent cough or pneumonia.

Fortunately, there are many ways to provide a supportive environment for your new child. This pamphlet will outline some of the information that may help you keep your family happy and healthy!

Leaving the NICU

Your baby has just arrived home after surgery for EA/TEF. What now?

Leaving a hospital with a brand new baby can present you with an overwhelming amount of questions: How do I feed my baby? How can I be sure that they are healthy and happy? How can I make sure that my entire family is supported through this change? In order to take on these challenges, there are some manageable steps to take in your first few days home from the NICU.

Build a team of healthcare professionals.

The care of children with EA/TEF can be complex; sometimes requiring many physicians, nutritionists, and speech pathologists. As you need them, find professionals you feel comfortable with and, if your team is willing, connect them via an email group to make sure that they all have the information they need to consult and make the best decisions they can.

Find a support network.

The stress of a new baby, particularly one with EA/TEF, can be immense. Find friends, families, or professionals to confide in.

Create a tracking system.

Write down and organize your baby's symptoms, growth, and feeding progress. Make sure to note any specific questions you have for your health care team.

Know what to do in case of emergency.

Work with your child's health care team to create an emergency plan.

Understand the tests.

Some common exams that may be used to monitor your child's health are: esophagram, endoscopy, multichannel intraluminal impedance pH monitor, modified barium swallow and esophageal dilation.

Celebrate the victories!

Try to remember that EA/TEF is rarely a life-threatening condition. Celebrate all of the progress and joy in your family every day!

What to Expect at Home

If you've just brought your new baby home it is likely that you'll begin to wonder whether or not some of their noises or behaviors are healthy. Each child is different, but there are some common attributes of EA/TEF patients. Here are some of the signs that indicate it's time to speak to the doctor:

Changes in eating behavior.

It is not uncommon for patients with EA/TEF to develop a stricture (narrowing of the esophagus). If your child is struggling more than usual during meal times, notify your doctor to make sure they don't have a **stricture**.

Recurrent or prolonged cough.

Most kids with EA/TEF have tracheomalacia (a softening of the windpipe that can make it floppy), putting them at risk for recurrent and prolonged cough. Your child will likely be referred to a pediatric pulmonologist (lung doctor) to address these issues. If there are any concerns of food entering the lungs, your child will also likely be seen by a speech pathologist.

Complaints of chest burn, belly pain or regurgitation in older kids.

Kids with EA/TEF are at an increased risk of gastroesophageal reflux (stomach contents traveling up to the esophagus), which can cause damage and long-term effects. As a result, your child will likely be on medication for acid suppression. If your child complains of symptoms mentioned above, bring them to the doctor for an evaluation. Reflux can also occur without symptoms and your doctor will be checking for this.

What's "*normal*" for children with EA/TEF?

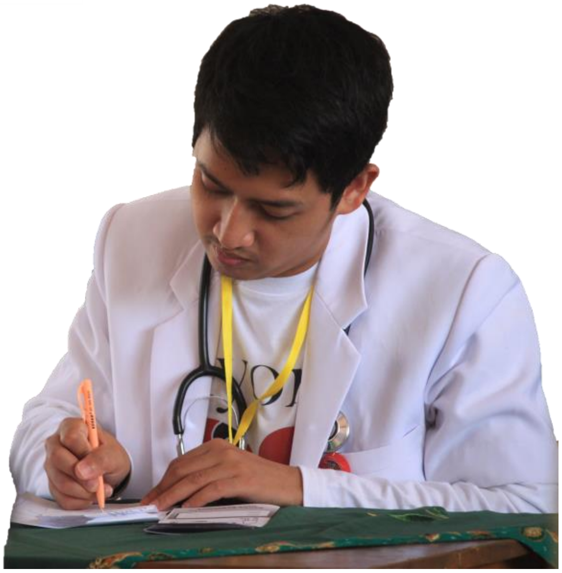
Trouble getting food down.

Due to the abnormal development of the esophagus in patients with EA/TEF, difficulty swallowing can happen. That's okay! As long as there's not excessive choking/vomiting or pooling of saliva, this is normal. Check page **5** for some feeding tips!

Persistent "barky" cough.

Many kids with EA/TEF have a loud "barky" cough. While this cough may seem concerning, it's common and not dangerous. Check page **6** for some strategies for handling the cough.

Meeting Your Child's Care Team



In order to provide, state-of-the-art comprehensive care, your EA/TEF team may refer your child to a number of different health care professionals. Here is a short list of providers, other than general pediatricians, that commonly see children with EA/TEF.

Gastroenterologist

As you already know, EA/TEF can cause lifelong digestive symptoms. Gastroenterologists will closely monitor your child's symptoms and their digestive tract to ensure long-term health.

Pulmonologist

As EA/TEF can affect both the digestive and airway tracts, it is often important to find a lung specialist to ensure the long-term health of your child's respiratory system. Pulmonologists will provide this service.

Cardiologist

Cardiologists specialize in care for your child's heart. This type of physician is not always necessary, but may be referred to children with both EA/TEF and heart complications.

Surgeon

You may already know your child's surgeon if they corrected your child's EA/TEF after birth. Your child's pediatric surgeon will correct any narrowing that occurs in your child's esophagus and assist you if your child has a feeding tube.

Dietician

One of the most important aspects of care for children with EA/TEF is to ensure that they are meeting nutrition needs. Dietician can help you plan a complete and healthful diet that works specifically for your child.

Speech Pathologist

Many of the obstacles to eating seen in EA/TEF may stem from difficulty swallowing. Speech pathologists can work one-on-one with your child to learn safe and effective eating habits.

Starting with Solids

Introducing textured foods can be challenging for children with EA/TEF. Each child is very different and will easily consume some foods while struggling with others. There are some simple rules to follow that apply to all kids and can help you to be successful during mealtimes.

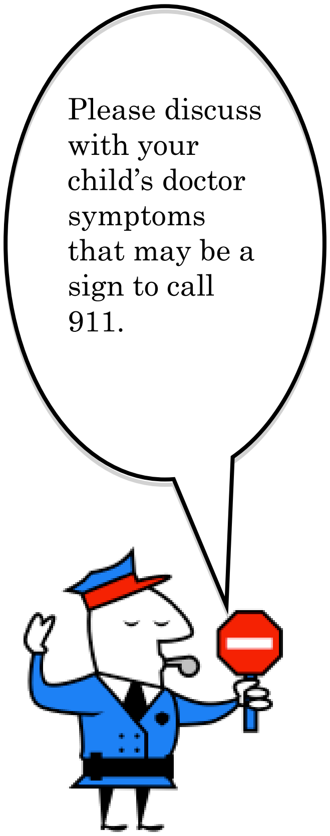
Count to three…

Three simple rules for safe eating:

1. **Keep watch!**
All meals and intake should be directly supervised. Food may need to be blended or cut into bite-sized pieces.

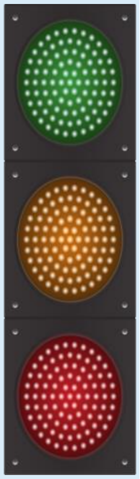
2. **Keep things moving!**
Many caretakers find that following food with sips of water helps get the food down in a way that is healthy! Try to encourage this behavior!

3. **Go S..L..O..W**
Feeding kids with EA/TEF will take time and patience. Make sure to take it slow and monitor for choking, coughing, or spitting up.



When introducing new foods to children with EA/TEF, it is not uncommon for choking, coughing, or spitting to occur. Here's how to know what's normal:

There may be no choking or coughing, in which case, this is a great food choice!



Some amount of choking or coughing will likely occur. Make sure to encourage slow and thoughtful eating.

If choking/coughing becomes excessive make sure to: take a break, make a note of the food that caused the problem, and keep calm (maintaining your cool can help your child- and any onlookers- to keep theirs as well)!

Going to School

A big question for parents of children with EA/TEF is: *How will my child's teacher handle their particular needs?* While this question is important, it does not need to be stressful.

You will likely want to talk to your child's caretakers about feeding and coughing. It will be necessary for any person feeding a child with EA/TEF to be familiar with common occurrences (coughing, spitting up, throat clearing) during meals. In addition, many teachers, students, and families will have questions about your child's "barky cough". Preparing your child's teachers before schooling begins will create a smoother transition into the classroom.

The first thing to do is select a school equipped to handle special instructions. Some schools may be more receptive to children with EA/TEF. During your search make sure to choose a school that will give your child the best care possible.

Once you have selected a school, meet with a principal or dean to find out which teachers and caretakers may be interacting with your child. Set up a meeting with these teachers, the principal, and a food worker if possible. Use this time to introduce them to the good and bad foods for your child. Encourage them to stick to good foods and let you do the experimenting at home. Ask them to look out for signs of a **stricture** (outlined on page **3**) and don't hesitate to have your teacher contact your doctor if there's a problem.

Finally make sure that all the people who care for your child understand that your child will have a barky cough and that this does not mean they are necessarily sick. As your child gets older, the frequency of this cough decreases, and will likely eventually go away completely.

Remember…

Celebrate the little things! Whether it's a new food, an inch of growth, or a healthy habit, make sure that you and your family are making time to be grateful for everyday victories. While EA/TEF requires lifelong management, it should not prevent your child from living a long and happy life. Encourage your little one to learn about their unique body. This will help them to accept and take ownership of their own care as they get older.

GI Kids

Help & Hope for Children
with Digestive Disorders

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