

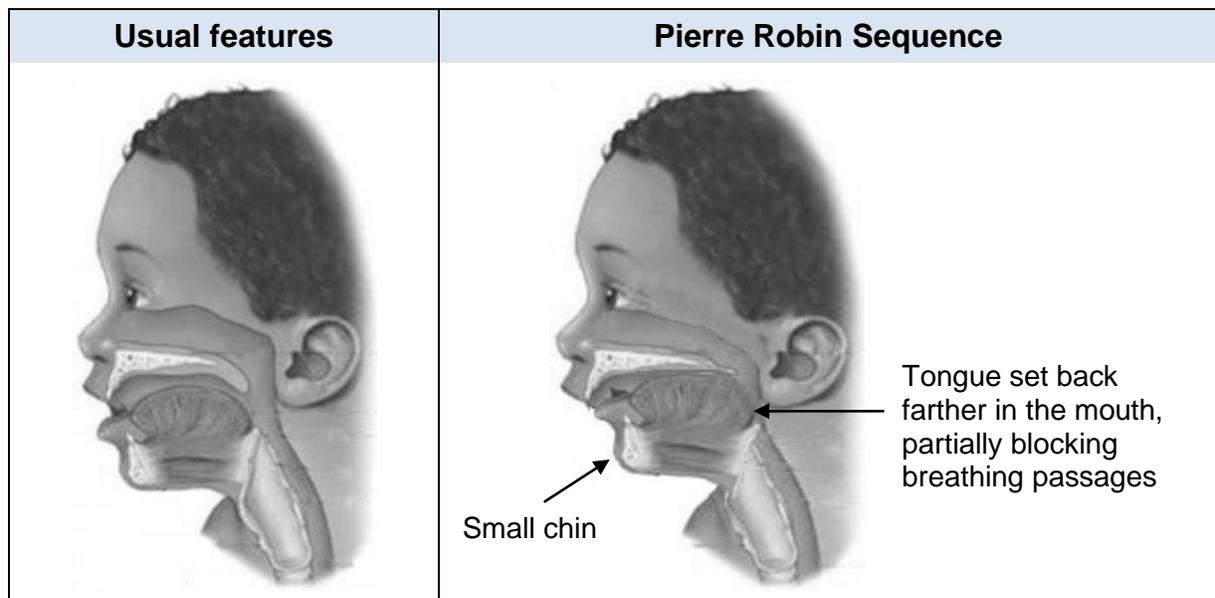
Pierre Robin Sequence

What is Pierre Robin Sequence?

Pierre Robin Sequence is the name of a condition at birth in which a baby has a small chin and a tongue that sits far back in the mouth. The baby may also have a cleft palate.

This combination of features can make it hard for the baby to breathe and feed, and he or she may not gain weight. These problems may start right after birth, or it may take several weeks for them to appear.

Pierre Robin Sequence is a temporary condition that most babies outgrow. It may last from several days to several months. The length of time is different for each baby. Each baby has their own 'story' that guides their care.



Learning your child's story

If your baby has the features of Pierre Robin Sequence, it is very important to check for any signs of breathing or feeding problems.

Depending on your baby's needs, you may meet many health care providers, including:

- Doctors
- Registered Nurses
- Respiratory Therapist
- Registered Dietitian
- Occupational Therapist
- Members of the Cleft Lip and Palate Team



Each person learns new information that adds to your child's story and guides his or her care. If team members recommend treatment, they will discuss the options with you including the risks and benefits. You will make decisions about your child's care together.

Pierre Robin Sequence affects babies in different ways, so each baby's care will be different. Some babies need help with breathing and feeding right away. Others may not develop problems for several weeks. You can expect your baby to be closely monitored in the hospital and after you go home.

On the next few pages, we describe some common treatment options for babies with Pierre Robin Sequence.

Your baby's health care providers will discuss the options recommended for your baby.

What helps with breathing?

Lying on the tummy

- For the first days in hospital, it can help to put your baby on his or her tummy. In this position, your baby's tongue stays forward. This can prevent the tongue from blocking the airway.

Nasal Pharyngeal Tube

- A small tube is gently passed through your baby's nose to the area behind the base of the tongue. The tube keeps the airway open, even when the tongue falls back. With this tube in place, your baby is safe in any position.
- Hospital staff will help you learn to care for the tube. Your baby can go home with it in place.
- While the tube is in place, your baby cannot be fed by mouth.

Tracheotomy

- If breathing problems are severe, a tracheotomy may be needed to keep the baby's airway open. A tracheotomy tube (trach) is put into the windpipe (trachea). Air goes in and out of the tube, bypassing the nose and mouth.
- Hospital staff will help you learn to care for the tube. Your baby can go home with it in place.

Your baby will have a car seat test before going home

- Before your baby can go home from the hospital, he or she will have a car seat test.
- Your baby is placed in his or her car seat for 90 minutes. During this time, a monitor will record your baby's heart rate and breathing.
- The purpose of this test is to make sure that your baby's airway remains open and he or she can breathe well while in the car seat.

What helps with feeding?

- If your baby has a cleft palate, he or she can suck and swallow, but will have problems creating suction. A special feeding bottle will help your baby get a fast enough flow of milk.
- Your baby may need to lie on his or her side for feedings. This position helps keep the tongue from falling back.
- If your baby has difficulty gaining weight, he or she may need a feeding tube for a while. A nasogastric or NG tube is gently passed through the nose and down to the stomach. Hospital staff will help you learn to care for the tube. Your baby may go home with it in place.
- A gastrostomy or G tube may be needed if it may be several months before your baby is able to take full bottles. The G tube requires surgery to put it directly into the stomach. Your baby will be able to bottle feed with the G tube in place.
- Reflux is a common problem for babies with Pierre Robin Sequence. Reflux is the case when the stomach contents come back up into the food passage (esophagus) or mouth. Positioning and medications can ease the problem.

Your baby's weight will be checked regularly

- If your baby is working hard to breath, he or she may burn more calories at rest and while feeding.
- Your baby's weight will checked often to make sure he or she is gaining enough weight.

Planning to go home

During your hospital stay, the health care team will help you learn how to care for your child. Before you leave the hospital, you and your family may meet with staff from the hospital and community. At this meeting, you will discuss your child's needs and plan his or her care in the community. The staff will give you information and support so that you can get equipment, resources and funding for your child's care, if needed.