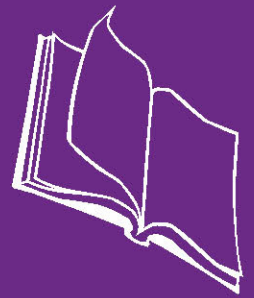


**The  
Emily  
Center**



# **How to Care for Your Baby with BPD (Bronchopulmonary Dysplasia)**



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# Important Information

Formula: \_\_\_\_\_

How to mix the formula: \_\_\_\_\_

\_\_\_\_\_

When to Feed: \_\_\_\_\_

When to do CPT: \_\_\_\_\_



## Who to Call For Help

Your Child's Primary Doctor: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Your Child's Pulmonary Doctor: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Your Child's Cardiac Doctor: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Your Home Health Care Nurse: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Your Oxygen Supplier: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Your Home Health Company: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Insurance Company: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Hospital Emergency Room: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Fire Department: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Electric Company: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

Ambulance: \_\_\_\_\_ Telephone Number: \_\_\_\_\_

# Introduction

Your baby has **bronchopulmonary dysplasia**, also called **BPD**. We want to help you:

- understand BPD
- learn the skills you need to care for your baby

Your baby's doctors and nurses are now planning to get your baby ready to go home. Some of the special care your baby is getting in the hospital may need to be done at home, too. This booklet will help you learn how to take care of your baby at home.

When babies have a serious condition, parents often feel out of control because they don't understand everything that is happening. However, once they learn about the illness and master home care skills, parents get their sense of control back.

Perhaps you, too, are feeling out of control and overwhelmed because you need to learn about BPD. This may seem like too much to handle right now, but don't give up. Like other families, you will also be able to take care of your baby.

Your nurse will show you how to do any treatments that need to be done at home. Your nurse will explain them to you, and watch you learn to do them. You will get written instructions that tell you what to do, like when to give medicines.

Your baby will not be sent home until he or she can be safely cared for.

The doctors, nurses, respiratory therapists and your social worker want to help you. If you have any questions, ask them. Write them down when you think of them, so you don't forget to ask.

This booklet is only an introduction to BPD. Your health care team will teach you the details. They will watch you practice taking care of your child. Don't try any skill alone until you are sure you can do all the steps. If you have any questions, ask the members of your child's health care team.



**This booklet will help you learn how to take care of your baby at home.**

# What is BPD?

In BPD, the airways and lung tissue are damaged, and cause a breathing problem that lasts a long time (**chronic**). Many babies who are premature or are born with medical problems need to be treated with breathing machines (**mechanical ventilation**) or oxygen to stay alive. These necessary breathing machines and the strong mixtures of oxygen probably cause some damage. BPD is seen most often in babies who have had these treatments.

Most babies with BPD need extra oxygen and medicine at home. The good news is, as babies grow they can get new lung tissue. It takes a long time for a baby with BPD to get better, but most do well over time.

The lung parts that are damaged in BPD are the parts that take in oxygen and put out carbon dioxide, or do the **gas exchange**. These are **bronchi** and **alveoli**. Your baby needs extra oxygen to make sure enough oxygen gets into his or her body.

Damaged airways in the lungs don't always behave normally. They tend to be twitchy and react to things. At times, airways may be too narrow to let air through easily. These **reactive** airways may go into **bronchospasm**. When this happens, your baby may have trouble breathing and **wheezes**, and his or her chest may suck in with breaths (**retractions**). When this happens, your baby needs to get rid of carbon dioxide and get more oxygen.

## **What kinds of problems do babies with BPD have?**

There are several problems babies with BPD tend to get. Your baby may have all, some or none of these problems.

- **Many respiratory infections**

In the first year of life about half the babies with BPD will be back in the hospital with a respiratory infection. Their damaged lungs catch germs easily. Page 14 of this booklet will show you how to help your baby avoid infections.

- **Slow growth**

Your baby may have trouble gaining weight. Babies with BPD use large amounts of energy just to breathe. Nurses and doctors will closely watch your baby's growth. Your baby may need a special formula to get enough nutrients and energy. If so, we will teach you how to mix this formula before your baby goes home.

- **Trouble with feeding**

Some babies with BPD have trouble with reflux and throw up quite a bit. We will teach you how to help your baby with this.

- **Congestive heart failure**

Lung problems can make the heart work harder. Medicine, fluid balance and diet can prevent or control congestive heart failure.

- **Trouble with electrolytes**

Too much fluid in the lungs can make it harder for your baby to breathe. Medicine that helps your baby get rid of extra fluid is called a diuretic. This fluid also contains electrolytes. Electrolytes are salts that flow in and around body cells. The fluid and electrolytes have to be kept in balance. Babies may need to get extra electrolytes added to formula or have the dose of their diuretic changed often. Your baby may need regular blood tests so the doctor can watch the electrolyte balance.

- **Developmental delay**

Some parents say their babies with BPD took longer to sit up or walk than other children. This may happen because they spent their first few weeks or months ill in the hospital. It may happen because the babies were premature. We will teach you ways to help your baby develop. Your baby may need physical therapy or speech therapy to do his or her best. If your baby needs this, your doctor will say so.

# Going Home

Your baby will need a lot of caring. This takes time. If you do feel tired or worried, relax. Your baby needs your love more than anything else.

When it's time to take your baby home, you may feel happy, anxious and afraid. If you know how to take care of your baby before leaving the hospital, you will have less to fear.

Your baby's nurses will work with you to decide what your baby will need at home. Ask questions! Know your baby before you go home together. Take care of your baby in the hospital.

Who else will take care of your baby at home? The other parent? A grandparent? Another relative or close friend? The people who stay with your baby need to be mature and able to handle your baby's special needs. They can learn about your baby's care with you.

To give your baby your best, you need to take care of yourself, too. If you have help and are not the only person who takes care of your baby, you will enjoy your baby more. Once you get home, there will be times when you need to go shopping or get away to relax. Don't expect to do it all yourself.

Think about your other children, too. They may feel all your attention is going to your baby with BPD. Plan time to play and go places together.

Remember, you are not alone. At times, it may be hard to care for your baby. Find someone who will listen to you talk about your feelings. This may be another parent who has a child with BPD, or your baby's doctor or nurse. It may be a social worker, clergy person or counselor. If you have trouble finding someone to talk to, ask your baby's doctor for help.

Whenever you need help or information, ask for it. If you don't know whom to go to, ask your baby's doctor.

# The Respiratory System

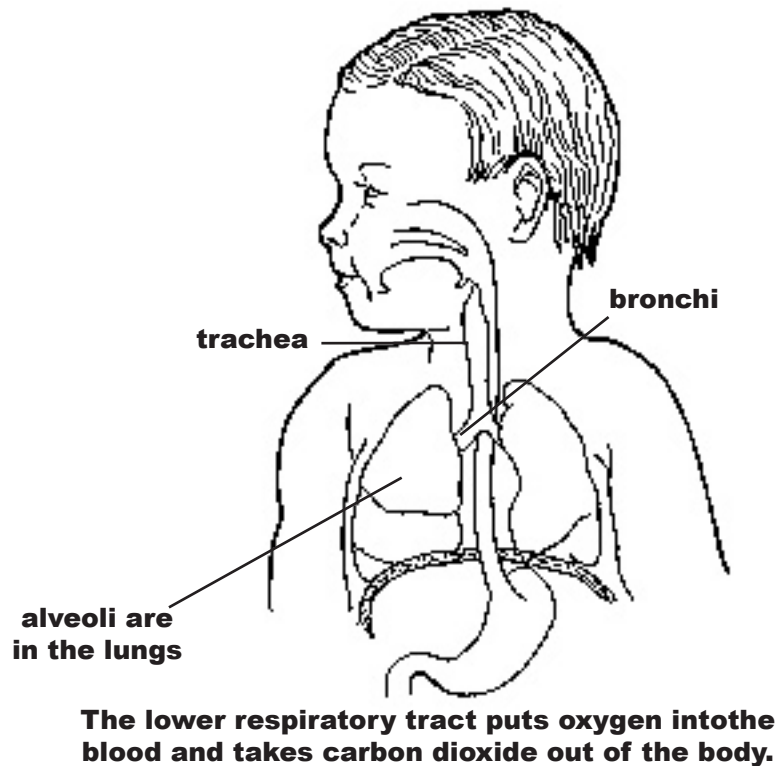
The upper and lower respiratory tracts together make the respiratory system.

The upper respiratory tract moistens and filters the air we breathe. It includes the:

- mouth
- nose
- throat

The lower respiratory tract is where oxygen is taken from the air we breathe and puts it into the blood. It also takes carbon dioxide out of the body. This is called gas exchange. The lower respiratory tract includes the:

- trachea
- bronchi
- alveoli



## How to Look at Breathing Problems

In the hospital, you will learn how to tell if your baby is breathing comfortably. Every baby with BPD shows some signs of breathing problems sometimes. Know your baby's normal breathing pattern, or baseline. This way you can tell when there are breathing changes.

You can tell if your child has breathing problems by looking at:

- **Skin color**

Lips and nail beds should be pink. If they are pale, white or bluish, not enough oxygen is going there.

- **Breathing rate**

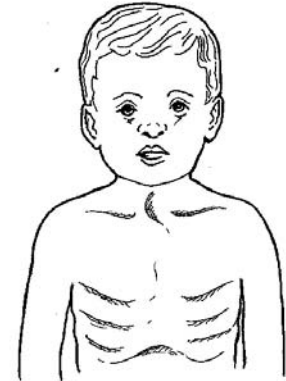
While your baby is asleep, count how many times your baby breathes in one minute.

This is called the **respiratory rate**. A resting baby with BPD should breathe less than 60 times each minute. Some babies breathe faster than others. A baby who is breathing too fast is working harder to get air.

My baby's normal resting breathing rate is: \_\_\_\_\_ times per minute

- **Retractions**

Retractions are when the skin between the ribs sucks in when your baby breathes. This happens when the baby works hard to breathe. Some babies with BPD always have mild retractions. When babies have trouble breathing, their retractions may suck in deeper.



**retractions**

- **Wheezing**

Some babies with BPD wheeze sometimes. Wheezing may be caused by bronchospasm or too much fluid in the lungs. If your baby's wheezing is louder or lasts longer than usual, your baby is having more trouble breathing.

- **Nasal flaring**

If your baby's nostrils flare open when he or she breathes in, your baby is having trouble breathing.

- **Mucus**

Mucus from the nose and mouth is usually thin and clear. When the mucus changes in color from clear to yellow, gray or green or there is much more mucus than usual, your baby may be getting an infection. Extra mucus makes it harder for your baby to breathe.

Normally, babies with BPD often have more than one of these signs. If your baby's respiratory distress gets worse, your baby will have more signs or worse signs.

# Treatment of BPD

We help babies with BPD to breathe and eat so they can grow new lung tissue. We give oxygen to help the body tissues and organs work and grow. Breathing problems are treated with medicine, mist and other things. Good nutrition helps your baby grow new lung tissue and fight off germs.

## Oxygen

To live, people need to take oxygen out of the air into their bodies. Babies with BPD have trouble taking oxygen out of the air into their bodies. So many babies with BPD need extra oxygen. The most common way to get extra oxygen is through a nasal cannula.

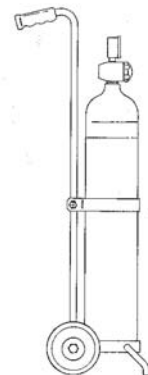


**a nasal cannula**

Your baby's doctor will tell you if your baby needs oxygen. A doctor needs to see your baby often, to make sure your baby is getting enough oxygen. Do not take the oxygen away from your child unless your doctor tells you to.

There may be times when it is best to increase your baby's oxygen, such as:

- When your baby is very pale or has blue gray skin (cyanotic)
- During times of crying
- When your baby has trouble breathing
- During feedings
- During chest physiotherapy (CPT)
- During sleep



**an oxygen tank**

Your nurse or doctor will tell you when and how much to increase your baby's oxygen at these times.

The oxygen company will bring your oxygen in two containers, one that stays in the house and one you can carry with you. The oxygen may come as compressed gas or liquid oxygen. In the liquid oxygen system you can refill the small tank you carry.

The vendor will teach you how to use the equipment safely. Here are a few safety tips:

- Do not drop the oxygen containers or let them tip over.
- Keep oxygen away from hot things like heaters, fires, flames and sparks.
- Do not smoke in the house where oxygen is used.

- Teach children not to touch the oxygen containers.

If you want to learn more about using oxygen, ask your nurse or doctor for a copy of the booklet, **Using Oxygen at Home**. (Check when done.)



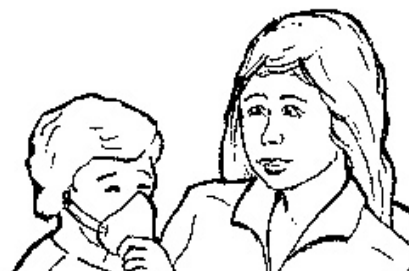
**Oxygen burns quickly. Keep oxygen away from hot things like heaters, fires, flames and sparks.**

## Mist Treatments

Sometimes it will be harder for babies with BPD to breathe. Your baby's doctor may treat this with medicine, which is given in mist. This lets your baby breathe in the medicine easily.

The mist is made of salt water (**saline**) and medicine. The medicine that is mixed in the mist helps keep your baby's airways open (**bronchodilator**).

The machine that makes the mist is called a nebulizer. You mix the medicine with the saline in the nebulizer cup. The machine pushes air through the mixture and makes a mist. If your baby takes oxygen, make sure it is still on during the mist treatment.



**The machine that makes the mist is called a nebulizer.**

Mist treatments are done before CPT. The mist loosens the mucus, the medicine opens the airways, and the CPT helps take the mucus out of the lungs.

The home vendor who brings the nebulizer will teach you how to use the equipment before you go home. Your baby's doctor or nurses at the BPD clinic can also answer your questions.

If you want to learn more about SVN machines, ask your nurse or doctor for the handout **How to Use a Small Volume Nebulizer**. (Check when done.)

## Chest Physiotherapy (CPT) and Postural Drainage

Not all children with BPD need chest physiotherapy. Chest physiotherapy (CPT) helps move mucus out of the lungs. Mucus falls from high to low. So part of CPT is postural drainage, where the baby is placed in different positions to drain the mucus out of the airways.

Another part of CPT is **percussion**. This is clapping on the chest and back using a vibrator or a small cup called a percussor. Just like tapping a Jell-O mold, clapping on the baby helps loosen mucus from the airways so it can come out.

The best time to do CPT may be before breakfast and before bed time. Sometimes mist is given before CPT, to loosen the mucus. Before you go home with your baby, a respiratory therapist or nurse will teach you how to do CPT.

If you want to learn more about CPT, ask your nurse for the booklet *How to Do CPT — Infants and Babies*. (Check when done.)

## Suctioning

After other treatments loosen the mucus, you need to help your baby get rid of it. Some babies can cough up their mucus, but sometimes you need to help.

Suctioning takes out the mucus. You can suction the mucus out of your baby's nose and mouth with a bulb syringe.

If you want to learn more about suctioning, ask your nurse for the handout *Using a Bulb Syringe*. (Check when done.)

## Apnea Monitor

Apnea means stopping breathing for a short time, but more than 20 seconds. There is a machine called an apnea/heart monitor that will sound an alarm if your baby's breathing or heart rate slows down or speeds up.

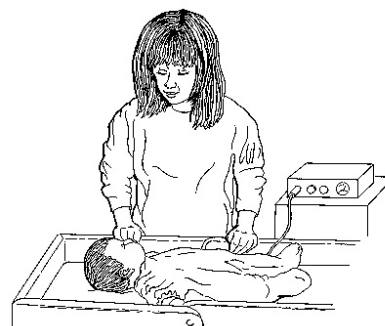
Phoenix Children's Hospital has an Apnea Management Program. Nurses will teach you how to use the machine before you go home with your baby. You will also be taught **cardiopulmonary resuscitation (CPR)**.



**Chest physiotherapy (CPT) helps take mucus out of the lungs.**



**a bulb syringe**



**Apnea means breathing stops for a short time.**

A nurse from the Apnea Management Program is always on call to answer your questions. You can call the Apnea Management Program at (602) 546-0910.

## Medicine

Some of the medicines used to treat BPD include diuretics and bronchodilators.

Diuretics keep extra fluid out of your baby's lungs. Since these medicines remove fluids, body salts (electrolytes) mixed in may be removed, too. So many babies on diuretics also need to take electrolyte supplements to keep them in balance.



Bronchodilators relax and open up the airways, letting air to go in and out easily. These may be given as a liquid by mouth, or in a mist treatment.

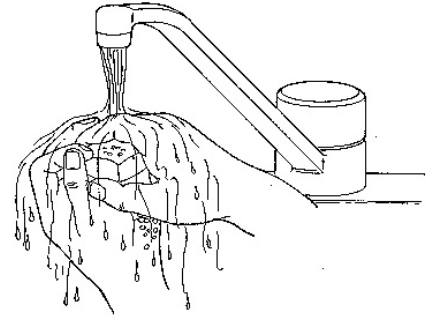
**Some of the medicines used to treat BPD include diuretics and bronchodilators.**

Your baby may need other medications to treat other problems. Nurses and doctors will tell you about your baby's medicines and answer your questions before you take your baby home.

If you want to learn more about your child's medicines, ask your nurse or doctor for handouts. (Check when done.)

## How to Avoid Infection

Babies with BPD do not fight off germs well. It is easy for them to catch colds and respiratory viruses, such as RSV. And in babies with BPD, these can lead to serious illnesses. So it is important to avoid infection. Here are some tips:



**All people who touch your baby should wash their hands first.**

- Wash your hands for 20 seconds with soap and water. All people who touch your baby should wash their hands first. Tell them why. Don't worry about hurting people's feelings. Nicely tell them your baby needs help to keep safe from germs.
- Young children usually don't wash their hands well. Your baby can play with his or her brothers and sisters, but other children should be kept away.
- When you visit the doctor's office, ask to wait somewhere away from sick children.
- Only people in your family should kiss your baby with BPD. Those germs are in your house and on your baby already.
- Anyone with a cold or virus should stay away from babies with BPD.
- Don't take your baby into crowds, like to grocery stores, church, malls or theaters.
- You may still have to care for your baby when you have a cold or virus. If you are sick, wear a hospital mask when you care for your baby. Ask your nurse or doctor where to get them.
- Help your baby keep away from quick changes in temperature.
  - Give your baby a bath in a warm spot.
  - Let fans blow near your baby, not on your baby.
  - Dress your baby for the weather. Dress your baby to be comfortable, not too warm or too cold.
- Make sure your baby gets immunizations on time. Baby shots against common illnesses (measles, mumps, rubella, diphtheria, pertussis, tetanus, polio and Hib) will help keep your baby healthy. Babies with BPD should also get a flu shot each fall. These illnesses are serious, and can kill a baby with BPD. If your baby has a fever or infection, your doctor may put off a baby shot until your baby is well.

## Food

Your baby needs healthy food to help grow new lung tissue and to fight off germs. Your baby also works hard to breathe, and needs more calories than babies who don't have BPD.



**Your baby needs healthy food to help grow new lung tissue and to fight off germs.**

Formula will give your baby the right amount of nutrients and fluid. Too much fluid can build up in your baby's lungs. Don't give your baby extra juice, sugar water or fluids.

A pediatric registered dietitian or nutritionist and your baby's nurse or doctor will tell you what foods meet your baby's special needs. They may show you how to add sugars (carbohydrates) or fat to your baby's formula.

- Ask your nurse or nutritionist to show you how to mix your baby's formula.  
(Check when done.)

## How to Mix Formula

A nutritionist or doctor will decide what is the best formula for your baby. Before you take your baby home, a nurse or nutritionist will show you how to mix the formula.

Make only enough formula for one day at a time (24 hours).

Once you open a can of liquid formula (ready to use or liquid concentrate), cover or cap the can and keep it in the refrigerator. You must use the whole can within two days (48 hours) or throw it out.

If you use formula powder, it is easiest if you use warm water and a blender. Mix enough formula for one day (24 hours) and store it in a clean, tightly-covered container in the refrigerator.

You may store the formula in baby bottles. Fill clean bottles with the right amount of formula. Keep them in the refrigerator, tightly sealed, with the nipple covered.

## Feeding Your Baby

1. Shake the formula.
2. Put the right amount of formula in a baby bottle.
3. Warm the baby bottle in a pan of hot water.
4. Put a few drops of formula on the inside of your wrist to make sure it is not too hot for your baby.

Your baby may have trouble breast feeding or bottle feeding. Every baby is different, but some reasons for feeding problems are:

- getting tired easily
- having trouble figuring out when to suck and when to breathe
- not able to suck yet (**immature sucking**)
- trouble breathing

Here are some ways to help your baby eat:

- Do mist, CPT and suctioning 30 to 60 minutes before you feed your baby. This will let your baby rest before eating. If you feed your baby before these treatments, your baby may throw up.
- Feed your baby in a quiet, calm place. This will help you both enjoy the meal.
- Sit your baby up to eat. This will help your baby breathe easier, and food will flow down into the stomach.
- Wake your baby up to eat. If your baby falls asleep during the meal, wake your baby up.
- Your baby works hard to eat, and may swallow a lot of air when eating. For every half-ounce or ounce of formula your baby takes in, stop the feeding and burp your baby.
- Find a nipple your baby likes. It is easiest for babies to suck a soft rubber nipple.
- Do not give your baby new food until your baby's doctor tells you to. All foods have fluids and minerals, and need to be added to your baby's diet very carefully.
- When you give your baby cereal, mix it with a little of the formula. This means your baby will have less formula to drink in that meal.

- Feed your baby cereal with a spoon. Do not put cereal in a baby bottle unless your nurse, doctor or nutritionist tells you to.
- If you feed your baby through an NG tube (nasogastric tube), give your baby a pacifier to suck on during the feeding. This will teach your baby that sucking brings in food.

## Feeding Over Time

When you are pregnant, the baby is developing. A baby who is born early is not fully developed. Babies who are born early have to catch up. First they have to finish the growing they would do in pregnancy, then they grow like new born babies.

We keep track of this by looking at how old your baby was when he or she was born, called **gestational age**. This is very important when we talk about feeding.

A baby born one month early needs to catch up. He is one month behind in development, compared to a baby born at nine months. Remember this.

If your baby was born early, he or she may not be able to eat from a spoon when three months old. That is because your baby needs to catch up first. Your baby will be able to eat with a spoon and drink from a cup, when his or her mouth and tongue have developed enough.

Babies who are not born early grow at about the same speed:

At birth: they can suck

At 2 to 4 months: they put hands, fingers and toys in mouth

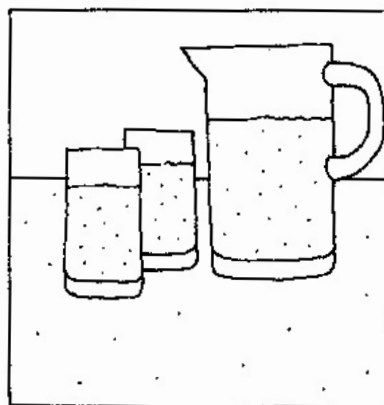
At 3 to 6 months: they can eat from a spoon

At 6 to 8 months: they can drink from a cup

## Fluids

Babies with BPD tend to hold onto fluid. This can build up in their lungs and make it harder for them to breathe. You may need to limit how much fluid they take in, or take medicine that prevents the build up of fluid.

Your baby's doctor or dietitian can figure out how much fluid your baby needs every day. Your doctor may say your baby may not have more than a certain amount of fluid in a day. This is called a **fluid maximum**.



**Your doctor may say  
your baby may not have  
more than a certain amount  
of fluid in a day.**

Every 24 hours, your baby should have no more than the fluid maximum. Your baby should not have too much less than the fluid maximum, either. If you feel your baby is too hungry, call the doctor. If your baby does not take in all the fluid for a feeding, add that amount to the next feeding.

The fluid maximum gives your baby all the water he or she needs for 24 hours. Do not give more than that. Your doctor will tell you when to give more fluids. If you mix cereal with milk, subtract that milk from the fluids your baby drinks that day.

Sometimes, even if you are very careful with feedings, your baby's body may have too much or too little fluid.

These can happen if your baby:

- holds or loses too much water
- drinks too much or too little
- has loose stools
- throws up



**Call your baby's doctor right away if you see these signs:**

#### **Signs of too much fluid (fluid overload)**

- irritability
- eats poorly
- works hard to breathe: has more retractions, nasal flaring, breathing faster, wheezing or noisy breathing
- skin color changes to pale or blue gray (cyanotic); needs more oxygen
- swollen eyelids, backs of hands, tops of feet or shins

#### **Signs of too little fluid (dehydration):**

- Decrease in the number of wet diapers.
- Urine looks very dark yellow (concentrated)
- Lips and inside of mouth are dry
- Lack of tears
- Unusual weakness or tiredness
- Skin is dry and loses its elasticity (stretch)

If your baby shows signs of too little fluid, do not give any diuretic medicine until you talk to your baby's doctor.

## Electrolytes

Electrolytes are minerals the body needs. One of these important electrolytes is called **potassium**. Diuretic medicine takes potassium out of the body and empties it into the urine. Therefore, your baby may need to take potassium every day.

Another electrolyte, **sodium**, is in the body and in table salt. Large amounts of sodium can cause a body to hold in water (**water retention**). Your health care team members may tell you not to feed your baby food that has large amounts of sodium or salt.

Canned food has a lot of sodium. If you make your own baby foods, do not make them with canned food. Before you season your food, you may put aside some to feed your baby. You may also give your baby food made for low sodium diets, like low sodium formula or fruit juices. If you cannot find these in a store, your pharmacy can order them.

Your baby may need regular blood tests. Blood tests show if your child needs to take in more or less electrolytes. As your baby grows, the amount of diuretics and electrolytes your baby needs will change.



**Large amounts of sodium can cause a body to hold water.**

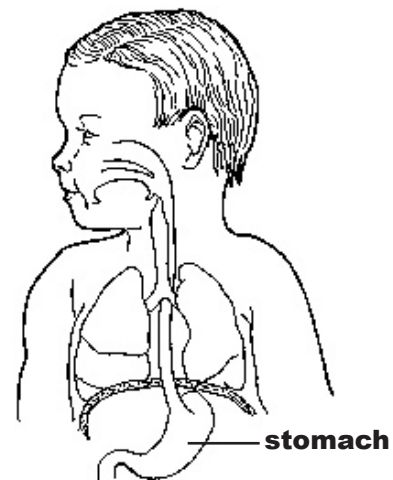
## Gastroesophageal Reflux (GER)

**Gastroesophageal reflux (GER)** is a backward flow of food from the stomach up to the throat. This happens when the muscle that usually closes off the stomach does not work. Feeding tubes and some medicines may keep this muscle from closing all the way.

This can be serious. Your baby can choke on the food that comes up, or the food can go into the lungs and cause an infection.

### How to Help Your Baby Have Less GER

- Have your baby sit up when you feed him or her.



**Gastroesophageal reflux (GER) is a backward flow of food from the stomach up to the throat.**

- Hold your baby for feedings. Never give your baby a bottle in bed.
- After feeding, put your baby on his or her right side. After feeding, do not put your baby in a car seat or lie on the back for at least 30 minutes.
- Put a pillow or towel under the head of your baby's mattress to raise it. This will keep your baby's head up and feet down. Do not put the pillow or towel under your baby's head.
- When you change your baby's diaper, don't lift your baby's feet higher than his or her head.
- For an hour after feeding, have your baby play quietly.

## Your Baby's Development

### Behavior

Behavior is how a person acts. It is different for everyone, including babies. Behavior is a result of mood, feelings, movement and how the person responds to stress.

Babies with BPD are often fussy, difficult or irritable. They may not like change. They may be hard to soothe, and may pull away.

Parents of babies with BPD may find this behavior upsetting. They may feel angry with the baby or with themselves. They may feel like they are not good parents. These are normal feelings.

You may have these feelings, too. Be easy on yourself. Here are some tips to help you:

- Know your baby. Learn what your baby likes and doesn't like. Learn your baby's favorite positions and sleep patterns. Learn what calms and soothes your baby.
- Teach your baby how to comfort him or herself.
- Keep things the same in your baby's life. Feed at regular times. Keep the same people around your baby. Keep your baby in the same places. When your baby is older, he or she will be able to handle change better.

## Cues

Babies with BPD work hard to breathe. They get tired easily. Learn how to tell when your baby needs a rest. Learn to read your baby's cues. Here are some cues babies with BPD may give when they need to rest:

- looks away, not looking at you eye-to-eye
- skin color changes, may be pale or flushed
- looks worried, frowns or grimaces
- stares, like he or she is looking through you
- gags, hiccups or spits up when not eating
- gets limp or stiff, arches back, change in muscle tone
- gets fussy, beats arms or legs

Make sure the other people who take care of your baby know these cues, too.

## Helping to Calm Your Baby

It takes energy to be fussy. A calm baby can use that energy to grow. Here are some ways to help your baby stay calm:

- Talk to your baby in a slow, quiet voice.
- Change your baby's position.
- Wrap your baby in a blanket.
- Slowly stroke the top of your baby's head.
- Give your baby a blanket or finger to hold.
- Put your baby's fingers into his or her mouth.

You can use the room or space to help calm your baby.

- Keep your baby in a space that is quiet and not too busy.
- Keep soft colors around your baby, like green, blue, gray or tan.
- Play soothing music.
- Don't make the room too bright.

## Hearing

Babies with breathing problems who spend a long time in the hospital may get ear infections. If the ear infection is not cleared up quickly, fluid can build up in the ears. This fluid may cause a hearing problem. Some, but not all babies with BPD may have hearing problems.

Good hearing helps your baby understand and learn. Babies with BPD should have their hearing checked regularly.

Your baby may get a hearing test while in the hospital, or soon after going home. There are two types of hearing tests: the **Brainstem Auditory Evoked Response (BAIF-R)** and the **Auditory Brainstem Response (ABR)**. Your baby will get medicine before the test so he or she will sleep through the test. These tests do not hurt.



**Babies with BPD should have their hearing checked regularly.**

Your baby's hearing will be checked again at the ages of six months and one year. But you, too, can watch your baby for hearing problems. Here are some signs of a baby who hears well:

#### Birth to 3 months

- Startles at loud noises.
- Gets calm when hears a quiet voice.

#### 3 to 6 months

- Tries to find where sound is coming from.
- Plays with rattles and noisy toys.
- Responds to voices he or she knows.

#### 6 to 10 months

- Understands simple words.
- Responds to noises around the home, like the phone or TV.
- Responds to a quiet voice.



If your baby does not show these signs, call your baby's doctor.

## Speech and Communication

As soon as babies are born, they start to learn the skills they need to understand and talk. Talking and playing with babies builds their **communication skills**. Here are some ways you can help your baby learn to understand and talk:

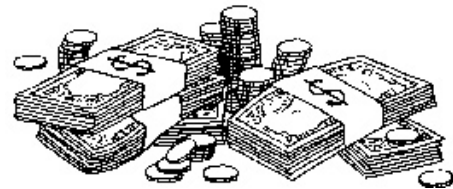
- Talk to your baby. Change your voice and pitch to get your baby's attention.
- Talk to your baby in full sentences. Let your baby hear all the words and how they flow together.

- Face your baby when you talk. Look your baby in the eyes.
- Hand your baby toys, so your baby will look at them.
- When your baby looks at something, talk about it. For example, if your baby looks at a ball, talk about the color and size of the ball, and show how it bounces.
- Babies need a lot of cuddling. When you talk with your baby, touch him or her softly and gently.
- When your baby makes sounds, smile, hug or touch your baby. If you pay attention to your baby's sounds, your baby will want to make more sounds. This will help your baby learn to talk.

## After Your Baby Goes Home

Before you take your baby home from the hospital, your health care team members will tell you the plan for follow up care. You will know how to take care of your baby at home, and when your baby will see the doctor next. If your baby needs a lot of treatments and medicines, a nurse may come to your home.

In the beginning, your baby may have many appointments to get tests and see doctors. But as your baby grows and your baby gets healthier, there will be fewer doctor visits. Some parents have trouble with getting to these appointments or paying for doctors, medicines or tests. Don't let transportation or money get in the way of getting the best treatment for your baby. Talk to your baby's nurse or doctor. They can help you see a social worker to help you with these problems.



**Don't let transportation or money get in the way of getting the best treatment for your baby. Talk to your baby's nurse or doctor.**

One doctor is in charge of your baby's health care team. This may be your baby's pediatrician or your family doctor. This doctor in charge is called your baby's **primary physician**. This doctor and his nurse will guide you in caring for your baby, give your baby shots (**immunizations**) and treat normal infections that children get.

The health care team also includes other doctors. Some babies see a lung specialist (**pulmonologist**), a heart specialist (**cardiologist**) an eye specialist (**ophthalmologist**), or

other special doctors. These doctors work together to make sure your baby gets the best care possible.

Babies with BPD may develop slower than other children. Time and therapy can help. An **occupational therapist (OT)** may work with your baby, and tell you how you can play with your baby to help him or her develop. Before you take your baby home, you can practice. Your baby's doctor may want your baby to see an occupational therapist several times.

You want to keep your baby safe from other people's germs, so your baby may only leave the house for health care appointments for a while.

When you leave the house with your baby, take all the things you need to care for your baby:

- food
- diapers
- diaper bag
- medicine
- bulb syringe
- oxygen
- apnea monitor
- toys
- stroller can help you carry all this with your baby.

Sometimes, you may be out of the house longer than you expected. Take enough supplies so you can stay out with your baby longer, safely and comfortably.

When your baby has a doctor's appointment, also take:

- a list of all the medicines your baby takes
- other medical records (test results, x-rays)
- a list of questions you have about your baby

When your baby sees a doctor, he or she will look at your baby. The doctor may also ask you questions about your baby's usual day, usual breathing, and how your baby responds to medicines and treatments. The doctor may take some of your baby's blood or do some other tests, like **oximetry readings** or **x-rays**. Ask the doctor questions if there is anything he or she does not explain well enough.

# When To Call Your Baby's Doctor

There is always someone you can call if you have concerns about your baby. If you think your baby is having trouble breathing, call your baby's doctor. Babies with BPD can catch colds and ear infections easily. Don't wait, because babies with BPD can get respiratory distress very quickly.

Do not stop giving your baby medicine. If you are thinking about stopping, call your baby's doctor. Make sure you get prescriptions refilled before they are used up.



Call your baby's doctor right away if you see these signs:

- fever
  - temperature higher than 100° F under the arm, or 101° degrees rectal.
- increased trouble breathing
  - pale or bluish skin
  - taking 10 to 15 more breaths per minute than usual
  - more retractions than usual
  - more wheezing or cough than usual
  - nasal flaring
  - more mucus than usual from nose and mouth
- change in behavior
  - very fussy, cannot be comforted, will not sleep
  - very sleepy, hard to wake
  - loose stools or throwing up
  - fewer wet diapers
  - won't eat, or eats less than normal
  - swollen eyelids, hands or feet
  - pulling at his or her ears

## Before You Call Your Baby's Doctor

When you call your baby's doctor, he or she will ask you certain questions. Your answers to these questions will help the doctor decide how to help your baby. Be ready. Before you call, know the answers to these questions:

- What is your baby's temperature? How did you take your baby's temperature?  
Did you give your baby medicine to treat the fever? How much? When?

- What is your baby's respiratory rate now? What is your baby's baseline respiratory rate? Does your baby need more oxygen? What other signs of breathing problems do you see?
- Is your baby eating? How much has your baby eaten in last 24 hours? Is your baby throwing up? How much? How often?
- How many wet diapers has your baby had in last 24 hours? Normally, how many would your baby wet? Does the urine look dark? Are your baby's lips or skin dry? Does your baby cry tears?
- Is your baby fussy? Is your baby working harder to breathe? Is your baby swollen around eyelids, hands or feet? Is your baby's skin pale or bluish?
- Is your baby hard to calm? Is your baby sleeping more than usual?
- What medicines did you give your baby, when and how much?

## Questions and Answers

Many parents with babies with BPD have the same concerns. Here are some of the questions we hear often, and their answers. Some of these questions may be the same as questions you have.

### Will my baby's lungs ever be normal?

For many babies with BPD, yes. Often it takes a year for babies to start to breathe easier. By the end of childhood, most have normal or near normal lungs. However, some babies with BPD get asthma.

Around the time your child is 5 years old, lung function can be measured by **pulmonary function tests**. Your child's doctor may check your baby's lungs with these tests. These tests have found that babies with BPD may have trouble getting oxygen in their lungs and blood for several years. But most children with BPD have normal pulmonary function tests by the time they are seven years old.

## **I am afraid I will not be able to care for my baby at home. What can I do?**

Your baby will not go home until he or she can be safely cared for there. When it is time, you will have what you need and will know what to do.

It takes a lot of time and a lot of work to take care of a baby with BPD. It should be the job of more than one person. A third person should learn how to take care of the baby, too, so the regular caregivers can have some time off. It would be best if this person does not have young children, too. Germs spread easily.

Share the work of taking care of the baby with BPD. Know that it is hard work but it will get easier as your baby grows. Give each other time away from the baby, to relax.

Other children in your family may feel the baby takes up too much of your time. They may want more attention. Make time to spend with them, too.

Remember, you are not alone. At times, it may be hard to care for your baby. Find someone who will listen to you talk about your feelings. This may be another parent who has a child with BPD, or your baby's doctor or nurse. It may be a social worker, clergy person or counselor. If you have trouble finding someone to talk to, ask your baby's doctor for help.

Whenever you need help or information, ask for it. Who might know the answer? If you don't know who to go to, ask your baby's doctor. If your doctor doesn't explain things so you understand, ask again, or ask someone else. You take care of your baby, and you are the most important person on your baby's health care team. You need to understand.

## **What should I do when my baby throws up?**

Babies with BPD tend to throw up more than usual. They throw up because mucus from their lungs, which they cough up and swallow, makes them sick to their stomachs. Also, when they work hard to breathe, they swallow a lot of air when they try to suck and swallow.

After your baby eats, put your baby down on his or her side, with the head of the bed up a little. Ask your doctor if your baby should sleep on his or her back.

When your baby throws up, turn your baby's head to the side, right away. This will make the food run out of the mouth. Then, suction your baby's nose and mouth with a bulb syringe, to get out any mucus and formula.

If your baby throws up right after taking medicine, call your baby's doctor. Ask if you should give the medicine again.



If your baby throws up again and again, or the throw up looks green or bloody, call your baby's doctor.

## Can I take my baby on an airplane or to the mountains?

Heights can make it hard for your baby to breathe. If your baby has trouble keeping up his or her blood oxygen level, it may not be safe to take your baby on an airplane or to the mountains. Up high, pressure changes, and oxygen levels drop. Pressure in a commercial airplane is about the same as if you were on a mountain (7000 feet). Talk to your baby's doctor before you plan a trip.



**Talk to your baby's doctor before you plan a plane trip.**

This can also be a concern if your home is much higher in altitude than your baby's hospital. We want to make sure your baby can breathe at home.

If you are thinking about moving, think about where the new home is, too. Talk to your baby's doctor before you make any changes.

## Why is my baby on digoxin, a heart drug, when BPD is a lung problem? My baby doesn't have a heart problem.

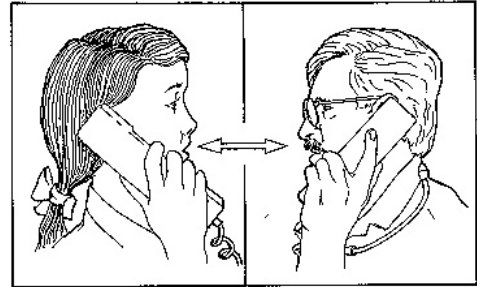
The heart and lungs work together. In BPD, the blood may have trouble flowing through the lungs. This makes the heart work harder. When the heart gets weak from working so hard, fluids build up in the body. Sometimes limiting fluids and diuretic medicines aren't enough to handle all this fluid. Sometimes a heart medicine, like digoxin, is given to make the heart pump stronger.

## I smoke. Will this hurt my baby?

Smoking is not safe around oxygen. Sparks can start a fire.

Smoke also irritates your baby's lungs. No one should ever smoke in the same house with your baby. It is best if no one ever smokes inside the house, or in the car your baby travels in.

Do you have other questions? Ask someone on your health care team.



**Do you have other questions?  
Ask someone  
on your health care team.**

## Your Baby's Home Care Plan

Before you take your baby home, you and the health care team will write down a plan for health care. It will be a list of your baby's medicine, treatments and feedings. Make sure you understand everything on the list, what you have to do, and how to do it before you take your baby home.

If there is anything you think you will not be able to do, for any reason, tell your health care team. They will work with you to make sure your baby will be safe at home.



If you have any questions or concerns,  
 call your child's doctor or  call \_\_\_\_\_

If you want to know more about child health and illness,  
visit our library at The Emily Center at Phoenix Children's Hospital  
1919 East Thomas Road  
Phoenix, AZ 85016  
602-546-1400  
888-908-5437  
[www.phoenixchildrens.com](http://www.phoenixchildrens.com)

#### Disclaimer

The information provided at this site is intended to be general information, and is provided for educational purposes only. It is not intended to take the place of examination, treatment, or consultation with a physician. Phoenix Children's Hospital urges you to contact your physician with any questions you may have about a medical condition.

Thursday, April 12, 2007 • DRAFT to family review  
#52 • Written by Sandy Parker, RN and Cindy Neubauer, RNC • Illustrated by Dennis Swain,

# Words to Know

alveoli	tiny air sacs where gases are exchanged in the blood; when filled with air they blow up like balloons
apnea	temporary periods of not breathing lasting longer than 20 seconds
baseline	normal pattern
bronchial tubes	tubes which carry air into and out of the lungs from the trachea
bronchodilator	medicine that helps the muscles of the airways relax and open wider
bronchopulmonary dysplasia (BPD)	An illness where the airways and lung tissue are damaged, causing a breathing problem that may last a long time
bronchospasm	when muscles of the bronchial tubes tighten and make it hard for air to pass through
chronic	lasting a long time
cardiopulmonary resuscitation (CPR)	a way to revive someone whose breathing or heart beat has stopped
chest physiotherapy (CPT)	chest treatment 'involving percussion and positioning which helps mucus move out of the lungs
cyanosis	when the skin gets bluish because there is too little oxygen in the body
dehydration	too little water in the body
developmental tasks	things children do around certain ages, like sit up by themselves at 8 months of age

distress or respiratory distress	trouble breathing
diuretic	a medicine which increases urine production and lowers the amount of fluid in the body
edema	swelling which comes from having too much fluid in the body
electrolytes	chemicals in and around body cells that control fluid balance and cell function
expiration	breathing air out of the lungs
fluid overload	too much water in the body
gastroesophageal reflux (GER)	a flow of food backward from the stomach up into the back of the throat
gestational age	how old your baby was when he or she was born, used to look at babies who were premature
inspiration	breathing air into the lungs
mechanical ventilation	to help someone's breathing with a machine like a respirator or ventilator
nasal cannula	oxygen tubing taped to the baby's face which gently blows oxygen to the baby's nostrils
nasal flaring	as the baby breathes in, the nostrils open widely, as if to pull more air in; a sign of respiratory distress
plugging	when mucus gets trapped in the lungs, keeping gasses from moving in and out
reflux	see: gastroesophageal reflux (GER)
respiratory distress	trouble breathing

retractions	the skin between, above, or below the ribs or breast bone sucks in as the baby is breathing
secretions	fluids, like mucus, made by the body for a purpose
vendor	the person or company who brings supplies or equipment to your home
wheeze	lung sound like a whistle that means the airways are narrowed and too small for air to pass through easily





## How to Care for Your Baby with BPD

Procedure/Treatment/Home Care  
Si usted desea esta información en español,  
por favor pídasela a su enfermero o doctor.

Name of Health Care Provider: \_\_\_\_\_ Number: 52

For office use: Date returned: \_\_\_\_\_  db  nb

## Family Review of Handout

Health care providers: Please teach families with this handout.

Families: Please let us know what you think of this handout.

Would you say this handout is hard to read?  Yes  No

easy to read?  Yes  No

Please circle the parts of the handout that were hard to understand.

Would you say this handout is interesting to read?  Yes  No

Why or why not?

Would you do anything differently after reading  
this handout?  Yes  No

If yes, what?

After reading this handout, do you have any  
questions about the subject?  Yes  No

If yes, what?

Is there anything you don't like about the drawings?

Yes

No

If yes, what?

What changes would you make in this handout to make it better or easier to understand?

Please return your review of this handout to your nurse or doctor or send it to the address below.

Fran London, MS, RN  
Health Education Specialist  
The Emily Center  
Phoenix Children's Hospital  
1919 East Thomas Road  
Phoenix, AZ 85016-7710

602-546-1395

[flondon@phoenixchildrens.com](mailto:flondon@phoenixchildrens.com)

**Thank you for helping us!**