

Helping Families Understand and Manage Pediatric Gastroesophageal Reflux

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Baby Chris was fat and happy. His pediatrician had never seen a baby gain weight so quickly, especially one who was born 5 weeks early. By 8 weeks old Chris had doubled his birth weight and was routinely consuming 64 ounces of breast-milk per day according to the pediatrician's scale. During his first year, he spit-up quite a bit, had 13 documented ear infections, and had several bouts with pneumonia and some wheezing episodes. His appetite was amazing, and he shrieked when the food wasn't offered quickly enough. He started on baby food at 6 months but weaned himself to an adult diet just days later after finding an unattended pizza and consuming all the toppings. He talked early, walked early, went to bed easily, slept soundly, was fiercely independent, and was generally easy to manage as long as he had free access to food.

Baby Katie was more challenging from the first few hours. She was found blue and not breathing in the well baby nursery. She couldn't keep either breast-milk or formula down and spit up about 75% of what she took in. She was quiet for the first several weeks but then the spitting-up started to be painful. She would go from happy to screaming as the milk dripped out of her mouth. The crying bouts would last for hours and the peaceful times nearly disappeared. She had to be held upright at all times and slept on her father's chest while he sat in a recliner. She woke an average of seven times per night screaming in pain. At 4 months old she completely refused to eat because eating was so painful. She fell off the weight charts, refused to walk, didn't like to talk, had a very limited diet, didn't sleep through the night till age 3 years, was fearful of doctors well into her teens, and was extremely clingy when she wasn't feeling well.

What do these two babies have in common? They both had gastroesophageal reflux disease (GERD). They are also both my babies (see Figure 1).

The Diagnosis and Treatment of GERD

AS A PROFESSIONAL or paraprofessional who works with children, learning about GERD will allow you to guide and support parents who may be coping with pediatric reflux. This article will give you a basic grounding in the disease and the treatments. But it may also help you to learn about the various perspectives in the medical community regarding the disease. The manner in which doctors in your community approach the disease can affect how successful your clients are at navigating the medical maze.

GERD has many possible treatments, and there are regional variations in how the medical community approaches the disease. The treatment that a doctor chooses first,

second, and last is affected by where the doctor trains, how long ago that training took place, a mentor's favorite treatments, the availability of testing equipment, exposure to messages from pharmaceutical companies, communication with colleagues in related specialties, familiarity with practice guidelines, attitudes toward pain control, a personal preference for parent reporting of symptoms versus testing, personal experience with side effects, time constraints of patient care in the clinical setting, insurance reimbursement for treatments or tests, and other factors. A recent survey of pediatric gastroenterologists demonstrated a wide variety of practice styles (Diaz et al., 2007). This study and recent commentaries (Sondheimer, 2006; Sutphen, 2001) also highlighted the current debate about whether reflux is under-recognized or overdiagnosed. Other studies have looked at whether GERD is undertreated or overtreated (Khoshoo, Edell, Thompson, & Mitchell, 2007). The debate is ongoing and not likely to be settled soon.

Some doctors love the challenge of pediatric GERD and others hate it. Treating GERD is part art and part science. GERD is rarely life-threatening and it isn't sexy. It is messy, it is time-consuming, the patients and parents are often highly distressed and sometimes demanding, the parents are highly involved because they are responsible for practical treatments and reporting symptoms, the symptoms vary widely from child to child, and there are no perfect tests to guide the diagnosis or treatment.

A member of the Pediatric Adolescent Gastroesophageal Reflux Association expressed her frustration:

My daughter had reflux several years ago and recently she was diagnosed with leukemia.

Abstract

Gastroesophageal reflux is a common medical problem affecting about 5% of otherwise healthy children. It is extremely common among children with special needs and affects more than half of children with cerebral palsy, Down syndrome, premature birth, and several other common conditions. The disease is becoming more widely recognized, but children with atypical symptoms may go undiagnosed for years. The author describes how early childhood professionals can help families in three important ways: first, to understand the disease thoroughly so parents can track the symptoms and work with their medical team; second, to learn homecare techniques that are an essential part of the treatment; and third, ways to support families when the daily demands of reflux pose a high emotional and physical burden.

Figure 1. Which one has GER?

PHOTOS COURTESY OF THE AUTHOR



Gestation 34 weeks, weight 7 lbs. 14 oz.	Gestation 38 weeks, weight 6 lb. 1 oz.
Weighed 13 lbs. at due date	Weighed 13 lbs. at 6 months
Very happy spitter	Inconsolable crying until 12 months
Slept through the night consistently at 6 weeks	Slept through the night (occasionally) at 3 years
13 ear infections, 2 mild pneumonias, and 3 mild asthma attacks in the first year	Apparent life-threatening event and apnea early on and aspiration pneumonia/sepsis at 6 months
Refused baby food after he discovered an unguarded pizza at 5 months	Refused feedings frequently and completely refused feedings at 5 months

Both had GER.

Symptoms of GER vary widely from one child to another.

In some ways, dealing with the leukemia was simpler. The doctors all agreed on what to do about it. But the reflux treatment was long, confusing, contradictory, contentious, and not particularly successful.

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) has launched a campaign to educate pediatricians about GERD. The American Academy of Pediatrics and TAP Pharmaceutical Products, Inc., also launched physician education programs.

Defining “Reflux”

THE SIMPLEST DEFINITION of reflux is backwashing of stomach contents into the esophagus. It is literally that simple.

Gastro (Stomach) + Esophageal (Throat) + Reflux (Backwash)

But, the word *reflux* is a lot like the word *depression*. It is commonly used to describe something that can range from trivial and annoying to something that is very serious indeed. When somebody says they are depressed, they might be telling you they are upset over a temporary situation or they might be telling you that they have been

hospitalized. The word depression covers a very broad spectrum. So does the word *reflux*.

There are many legitimate ways to describe the various levels of reflux (see box, Levels of GERD Severity). It is difficult for parents to believe that such a common medical problem doesn't have a more precise definition. In June 2001, NASPGHAN released official “Guidelines for Evaluation and Treatment of Gastroesophageal Reflux in Infants and Children” (Rudolph et al., 2001). This groundbreaking document is the best attempt so far to gather all the knowledge about reflux into a single place and to give doctors suggested courses of action to follow with their patients. The committee of doctors who wrote the Guidelines defined GERD this way: “Gastroesophageal reflux disease (GERD) occurs when gastric contents reflux into the esophagus or oropharynx [mouth / throat/nose] and produce symptoms” (p. S4). The Guidelines were also approved by the American Academy of Pediatrics and are currently being updated.

Confusing Terminology

If a child has many reflux events and is gaining weight very slowly, do we call this reflux the condition/illness or reflux the disease? If a child has many reflux events and

is become uninterested in eating, do we call this gastroesophageal reflux (GER) or GERD? And what word do we use when the number and frequency of episodes is clearly excessive but there is no measurable damage?

In real life, reflux does not have neat little labels (see Table 1) that make it clear exactly which category a child fits into. Susan Orenstein (1994) outlined when to use the term “reflux disease” in “Pediatric Gastrointestinal Motility Disorders”:

Since reflux is present in normal individuals, a continuum from normal to diseased exists with respect to gastroesophageal reflux. We should not define reflux disease simply by the deviation from normal values of frequency of duration: we should demand that symptoms, harm, or disability must be produced to meet our definition of disease. This may be difficult to determine, however. Does the patients who has pain induced by acidification, but who does not have histologic esophagitis [damage to the esophagus] or esophageal dysmotility [poor muscle contractions in the esophagus], have reflux disease? If so, it may often be missed. Does the patient who has normal reflux frequency, but who occasionally aspirates refluxate [stomach contents enter the lungs], have reflux disease? Certainly, but this course of events is often extremely difficult to document. (p. 62)

LEVELS OF GERD SEVERITY

Reflux—The Normal Event

The simplest definition of reflux is the backwashing of stomach contents up into the esophagus and occasionally out of the mouth. In fact, the word *reflux* is Latin for “reverse flow.” But this process isn’t a disease—it is a normal process that happens to almost everybody after meals. Adults call it a “wet burp” and in babies, wet burps often come up all the way out of the mouth and become known as “spit up.”

When babies spit up frequently, in a large quantity, or both, the parents often get quite worried even though the doctor will view the spitting as more of a laundry problem than a true medical problem. Occasional episodes of reflux are very seldom cause for alarm. Even a bit of spitting up after every meal can be perfectly normal and harmless (at least to the baby). Doctors often refer to this as “physiologic,” “normal” or “garden-variety” reflux.

Reflux—The Condition or Illness

Most people, including doctors, use the words *condition*, *illness*, and *disease* to mean the same thing, but they aren’t quite the same. The medical definition of a *condition* is an excessive amount of what healthy bodies normally do. In this case, we are talking about an unusually large number of reflux episodes. A child who experiences an excessive number of reflux episodes may require a lot of extra work, but this is really a condition, not a disease.

In medical lingo, an *illness* is when the patient or their family quite rightly believes there is a problem but it isn’t serious enough for the doctors to call it a *disease*. A child who fusses a lot during feeding may be experiencing reflux that makes her parent know that something is wrong, but the doctor may not think the problem is severe enough to treat with medication. It is quite natural for parents to be worried when a child is frequently doing something that other children only do occasionally. Excessive reflux events or crying can be quite stressful on parents and the whole family.

Reflux—The Disease

Doctors define gastroesophageal reflux *disease* (GERD), as *reflux episodes that cause some sort of measurable problem or consequence such as pneumonia or failure to thrive* (Sondheimer, 2006). Defining the words *problem* and *consequence* and *measurable* can also make it tricky to identify the disease.

Some practitioners argue for calling the child’s situation a disease (GERD) when the child has *significant* problems and call it a condition when the child has only *insignificant* problems from the reflux episodes. This is a great idea, but then we are back to defining more confusing terminology. In reality, reflux *disease* should probably be called reflux *syndrome*. A syndrome is a medical problem with a variety of different symptoms and each patient has different symptoms.

Statistics

WHEN MY DAUGHTER was diagnosed with GERD only 72 hours after her birth in 1990, the disease was considered to be very rare in children (Callahan, 1998). The rare classification disappeared over a decade ago, but there is still not 100% agreement about how common the disease is. Harmless reflux episodes are very common in infancy with as many as 50% of otherwise healthy babies spitting up in the first few months of life. About 20% of babies (1 in 5) have so many episodes that their parents get a bit worried (reflux the condition; Nelson, Chen, Syniar, & Christoffel, 1998). A much smaller percentage of children have reflux disease.

Recent research has shown that reflux is quite common and can affect children of all ages. In most children, it is a short-term problem of infancy lasting a few months but it can also be chronic and last for years (Gold, 2006). It can be difficult to discern between symptoms of colic and reflux (Berkowitz, Naveh, & Berant, 1997; see sidebar, Is It Colic or Reflux?). It is hard to get exact estimates because the definition of reflux has changed frequently. Over the years, each study has used a slightly different definition of reflux, and opinions about how many children have reflux have changed dramatically in the past few decades. When doctors first started studying reflux, they thought it only affected adults. By the middle of the last century, reflux was known to exist in children but it was believed to be very rare. The belief was that it only affected a few infants (mostly boys) and mentally handicapped older children. It was believed that all infants stopped refluxing by their first birthday (Gold, 2006).

One researcher conducted three surveys of parents and children asking about symptoms of reflux (Nelson, Chen, Syniar, & Christoffel 1997, 2000; Nelson, Mulvihill, Peters, & Kothari, 2007). The results showed 2–18% of the otherwise healthy children experienced symptoms indicative of GERD. But researchers in another study reviewed 5,718 pediatric medical records in an entire county and found only a handful of charts where the term GERD appeared. (Chitkara et al., 2007) Yet pediatricians in that same

Table 1. Terms Used to Describe Reflux

Terms that may be used to describe		
Reflux—The Normal Event	Reflux—The Condition or Illness	Reflux—The Disease
Physiologic reflux	A touch of reflux	Gastroesophageal Reflux Disease
Garden-variety reflux	Wait and Watch reflux	GERD (often pronounced to rhyme with bird)
Spitting-up	Mild reflux	Heartburn (often used to mean the same as GERD, but it really just describes one particular symptom)
Britons call spitting-up possetting or spilling	Excessive reflux events	Acid Reflux Disease (this term is often used but is only 99% accurate)
Wet burp	Gastroesophageal Reflux (GER)	Non-Erosive Reflux Disease (NERD)
Regurgitation	Excessive spitting-up	Laryngo- Pharyngeal Reflux (LPR)
Harmless reflux episodes	Dr. Sears says, “the Hurting Child”	
Volume reflux of infancy		
Non-acid reflux events		
Happy spitter		
Gastroesophageal Reflux (GER without the word disease added)		
Emesis (this is actually a word for the stomach contents)		

Adapted from Pulsifer-Anderson, 2007, p. 9.

county that same year reported that GERD is extremely common (several personal conversations).

A meta-analysis of all the available statistics concluded that about 7 million children in the United States alone experience GERD (Mattson Jack, 1995). In 2006, 2 million children in the U.S. took prescription medicine for digestive problems, mostly reflux (Medco Health Solutions, 2007).

Asthma and reflux often go hand in hand. Reflux episodes are one of the more common triggers of asthma episodes. Depending on the study criteria, about two thirds of asthmatics have documented reflux (Saglani et al., 2006). The relationship of asthma and reflux may be more complex because both can be triggered by allergies, and the violent chest movements of an asthma attack can provoke the regurgitation of stomach contents (Ruigómez et al., 2005).

Anyone caring for children with birth defects of the mouth, throat, chest, heart, lungs, or abdominal area should be alert for reflux symptoms (Saedon, Gourgiotis, & Germanos, 2007). Reflux is also common in any disease such as cerebral palsy that is neurological or neuromuscular in origin because digestion is a highly intricate function involving many muscles and nerves. Reflux is so common in premature babies that they are generally positioned with their upper body elevated and are often medicated “in case” they have reflux. Evidence for elevated positioning is shaky (Martin & Hibbs, 2006). Children with Down syndrome are highly susceptible to respiratory problems and tooth decay, and many researchers have demonstrated that reflux is a frequent culprit (Bell, Kaidonis, & Townsend, 2002; Mitchell, Call, & Kelly, 2003). Early childhood professionals who care for children with any other syndromes should be sure to ask if reflux is common for children with that particular syndrome.

Symptoms

TYPICAL” SYMPTOMS OF GERD include excessive spitting up, fussiness and poor weight gain (Rudolph et al., 2001). The list of atypical symptoms is much longer.

Pain

Most, but not all children with reflux feel significant pain. The pain can manifest as irritability, constant or sudden crying, “colic,” back arching, abdominal pain above the belly button, chest pain, heartburn or burning sensation in the esophagus, painful swallowing or the sensation that food is stuck, pain-based behaviors such as aggression or clinging, and poor sleep habits or frequent waking. In a few children, the pain



PHOTO: EMILY J. RIVERA

Excessive spitting up is a typical symptom of GERD.

is perceived in the shoulder joint or shoulder blade rather than the chest or abdomen. The pain of reflux can be extreme. Many adults who experience their first bout of reflux call an ambulance thinking it is a heart attack.

Regurgitation

Most, but not all, babies with reflux regurgitate frequently. Regurgitation is less common with babies older than 6 months. In older babies and children, reflux usually becomes “invisible,” “silent” or “occult” which means it goes back down rather than coming out of the mouth.

Regurgitation may manifest as frequent spitting-up, vomiting, frequent wet/sour burps, wet hiccups, food coming part way up or food coming up more than 30 minutes after eating. Rarely, children with reflux experience nausea or projectile vomiting.

Eating

Many children with reflux develop an extreme pickiness about foods or textures, food intolerances, refusing food, eating only a few bites despite hunger, eating only when sleepy, gagging, choking, poor weight gain, or

IS IT COLIC OR REFLUX?

Colic	Reflux
Crying more than 3 hours/day, 3 days/week	Crying may occur on and off all day and night.
Happy early in the day with fussiness building as the day goes on.	Often fussy or miserable all day. Some babies are happy with sudden bursts of crying.
Starts when child is about 3 weeks old.	Reflux may be present from birth but may only start to hurt after a few weeks.
Crying is most intense in the evening.	Babies with chronic pain often become overwhelmed at the end of the day and get fussier.
Tends to resolve after 3 months (at about 4 months of age).	Reflux often peaks at 4 months. Crying may get significantly better when the baby starts solid foods and sits up but doesn't usually stop overnight.
Parents interpret the crying as digestive pain, but researchers say there is no cause.	Crying is caused by digestive pain. The baby may cry more when fed or after meals or right after burping.
Colic and reflux may exist together. A few parents report their children still have bouts of crying in the evening even though the reflux is under control and all other symptoms are gone.	

Adapted from Pulsifer-Anderson, 2007, p. 15.



Babies with GERD need to be burped thoroughly.

even weight loss. On the other hand, reflux feels quite a bit like hunger and some children with reflux may eat when they experience reflux. A few will gain excessive weight which can in turn trigger additional reflux. Many children with reflux instinctively avoid trigger foods and may avoid other foods due to fear. It is common for children with reflux to eat only white foods.

Respiratory

Minor respiratory symptoms such as bad breath, constantly runny nose, frequent sore throat, frequent ear infections or congestion can be symptoms of reflux. More significant respiratory problems such as upper respiratory infections, sinus infections, ear infections, bronchitis, croup, wheezing, asthma, nighttime cough, nagging dry cough, throat clearing, noisy or labored breathing, a noisy inhale called stridor, hoarse or deep voice, or vocal cord nodules are less common. A few children with reflux experience pneumonia, apnea, or “awake apnea” episodes called obstructive apnea or laryngospasms.

Miscellaneous

There are a number of other symptoms and clues that can be associated with reflux, including headaches, excessive salivation and drooling, hiccups, intolerance of pressure on the stomach, needing to be held upright, or tooth enamel erosion or “moon craters” in teeth. Some children with reflux have esophagitis but significant esophageal damage such as ulcerations, strictures, Barrett’s Esophagus or precancerous changes are quite rare in children. A few children experience peculiar

totocolis-like neck arching called Sandifer’s Syndrome. In some children, reflux provokes vagal nerve irritation resulting in variable heart rate/blood pressure and fainting.

Diagnosis and Testing

THE NASPGHAN GERD Guidelines (Rudolph et al., 2001) do not recommend any medical testing for babies with typical reflux unless they have unusual symptoms; warning signs of other diseases; onset after 6 months of age; or the presence of serious complications such as vomiting bile or blood, blood in the stool, weight loss, or dropping off the weight chart. Testing might be necessary if the child doesn’t respond to treatment or if the symptoms are confusing. The Guidelines noted that “In most infants with vomiting, and in older children with regurgitation and heartburn, a history and physical examination are sufficient to reliably diagnose GERD, recognize complications and initiate management” (Rudolph 2001 p. S2).

Available Tests

The most common test is an empiric trial of medication to confirm the diagnosis. Although some diseases have an exact test that can tell whether the patient has the disease, it is not that simple with reflux. In fact, the most common “test” for reflux is a trial of medication. If the symptoms get better, the diagnosis is confirmed. This is called “empiric” testing.

A contrast X-ray of the upper gastrointestinal area is a fairly common test. It allows for good visualization of the stomach and esophagus. It is not used to diagnose GERD, but it

is used to rule out hernias and birth defects of the stomach. A variation of this test called a swallow study can be used to help determine the cause of choking and gagging and other swallowing issues.

A pH probe is an acid monitoring device that measures the acid level in the esophagus and gives an indication of reflux severity. The test also measures the frequency and duration of reflux episodes. The probe records data and provides the doctor with detailed information about the reflux events. The data is complex and often entered into a computer scoring program to help the doctor grade the severity. For instance, if a child has one very long acid event, it may be more important than a large number of short events.

A pH probe test is considered to be an excellent test to confirm reflux, however, a few children with significant reflux have had “unremarkable” or “negative” pH probe tests on occasion. This happens when reflux events are not acidic enough to register on the probe but may still be acidic enough to cause symptoms such as pain.

Variations of the pH probe have been invented to address the shortcomings of traditional probes. Most machines have dual probes. An intraluminal impedance adds a series of sensors that detect the presence of liquids whether or not they are acidic. An airway probe can detect incidences of acid vapors in the pharynx. These two variations are not yet widely available.

An endoscope is a flexible fiber optic tube attached to a camera that allows a doctor to see into the body. It allows the doctor to view the walls of the esophagus, stomach, and the upper part of the intestine. Biopsies of the esophagus and stomach are generally taken during an endoscopy so the lab can check for microscopic damage and the presence of bacteria or white blood cells.

A scintigraphy or a scintiscan is often referred to as a milk scan or delayed emptying test. It is used to document delayed gastric emptying. A doctor may also use scintigraphy to detect aspiration of food into the lungs.

Because food allergies can mimic GERD, it is fairly common for elimination diets or allergy testing to be tried with children who have unresponsive GERD.

Practical Treatments for GER and GERD

CHILDREN WITH GER and GERD can generally benefit from upright positioning, careful eating, and avoiding things that aggravate reflux (Orenstein & McGowan, 2008; Shalaby & Orenstein, 2003). Collectively, these treatments may be called homecare tips, conservative therapy, reflux precautions, or lifestyle changes.

Positioning

Doctors generally recommend that babies and children with reflux be upright, particularly after meals. Some children seem to be highly sensitive to positioning. Any child care provider can tell you about a child who simply could not lie down after meals because the child was guaranteed to spit up or vomit. Other children can lie down but only if they are placed with their upper body elevated. Some will show a distinct preference for faceup or facedown positioning.

Scientific studies of upright positioning have not demonstrated consistent efficacy. Various studies looked at a facedown or faceup positioning; seated faceup or lying faceup; left side or right side after meals; and with or without positioning devices (Bhat, Rafferty, Hannam, & Greenough, 2007; Corvaglia et al., 2007; Maggio, Schäppi, Benkebil, Posfay-Barbe, & Belli, 2006; Orenstein & Whittington, 1983). Some researchers concluded that positioning can be effective but is too much of a hassle (Orenstein, 1990). In 1992, the American Academy of Pediatrics ruled that babies with reflux might be safer sleeping face down (American Academy of Pediatrics Task Force on Infant Positioning and SIDS, 1992; Orenstein, 1992; Orenstein, Mitchell, & Ward, 1993), but that exception disappeared from later statements regarding the Back to Sleep Campaign. (American Academy of Pediatrics Task Force on Infant Sleep Position and SIDS, 2000, 2006).

Rather than dissecting specific studies and policy statements that are highly confusing and contradictory, parents and professionals can use careful observations of the child in question to see whether positioning helps. In children who do not spit up copiously, caretakers will have to pay attention to other symptoms such as wet burping, gulping motions, squirming, arching, and fussing.

Some parents instinctively adjust the baby's position without even being conscious of it. Other parents need help observing their child to see if the child reacts better to being upright. Does positioning make more or less of a difference after meals? Does a change in positioning help the child sleep better? Does movement help or make symptoms worse? Does this baby like to be held and comforted, or is she more comfortable with some elevating device like a wedge pillow or seat? Is she safer? Is she comfortable sitting, or do her hips need to be straight? Does she need to be elevated by several inches or just a small amount? Some parents naturally jiggle babies and might need to learn to sway rather than bounce. Careful observation may be needed to determine whether any measures provoke gagging, choking, or coughing.

Positioning seems to make very little difference for some babies and children. This



PHOTO: ©STOCKPHOTO.COM/BRENT DEVEL

Reflux is very common in premature babies.

can be because the level of reflux is so high that the symptoms are nearly constant. As the baby gets older, the frequency of spitting up will generally diminish, and positioning might seem to make more of a visible difference. The efficacy of positioning might only be noticeable if he is on medication that reduces the baseline of the symptoms. Or it could be that positioning doesn't really help him.

For babies who are sensitive to positioning, the purchase of positioning devices is an option that may help the family significantly. Getting a good night's sleep can make a huge difference to the health of the child and her parents. Getting to set the baby down for a few minutes can help the parents cope with the caregiving burden.

Patients with reflux are generally advised to avoid eating large meals.

There are over a dozen reflux positioning devices on the market. You can help your clients by investigating the various devices and options or helping the parents create a safe option if they can't afford to purchase one.

Small Meals

Patients with reflux are generally advised to avoid eating large meals. This is particularly problematic with babies because their normal meal size is very large compared to their body size. Offering smaller meals much more frequently can be very helpful. Nursing moms often find that offering only one breast per feeding can be very effective (Barmby, 1999).

Encourage the parents to talk to the pediatrician about how much their baby is expected

to eat in a day and how often the baby should come in for weight checks. Encourage the parents to follow the baby's cues and report if the baby's intake differs significantly from the doctor's expectations. Both underfeeding and overfeeding are common in babies with reflux and need to be addressed by the doctor. First-time parents may need some help observing whether their child has unusual eating patterns.

Thickening Liquids

A traditional treatment for reflux is to thicken the baby's formula with cereal. This seems to be quite beneficial for some children (Chao & Vandenplas, 2007; Khoshoo, Ross, Brown, & Edell, 2000; Wenzl et al., 2003) but it can induce coughing in other children (Orenstein, Shalaby, & Putnam, 1992). There are many tricks to thickening formula and adjusting the nipple size to accommodate the thick texture. Thickening breast-milk is more difficult because enzymes in the breast-milk often break up the cereal and it gets thin again. Thickening breast-milk can disrupt the nursing relationship and should be tried cautiously if at all (Barmby, 1999). Parents should always consult with their health care provider before trying any intervention.

Avoiding Triggers

Some foods can trigger reflux because they relax the sphincter at the top of the stomach (e.g., alcohol, most types of mint, chocolate, caffeine). Some increase the production of acid, which makes reflux episodes more painful and potentially more damaging (e.g., citrus, tomato products, spices that add heat, vinegar and sour condiments). Some foods take longer to digest because they



Some foods can trigger or increase the severity of GERD symptoms.

contain fat (e.g., rich sauces, fried foods, high fat meats, pastries with high fat content or frostings, cheese). Foods with skins, seeds, or tough fibers can also be hard to digest (e.g., stringy meats, apple skins, grapes, raisins, celery). Foods that cause constipation can increase reflux episodes by slowing the whole digestive system (e.g., apples, bananas).

Formula is harder to digest than breast-milk. Breast-feeding is generally the best choice for all babies, but moms who are nursing babies with reflux often need practical tips and support (Barmby, 1999). The pediatrician may recommend trying different formulas, especially hydrolyzate or even amino acid formulas if they suspect that the reflux is due to a food intolerance or allergy. Parents should always consult their pediatrician before switching formulas.

Burping

Babies and children with reflux have more episodes when they need to burp. Avoiding foods that increase burping is important. Cabbage, onions, broccoli, cauliflower, beans, garlic, airy foods such as cake, and bubbly foods such as sodas can all increase stomach gas and trigger reflux. Babies need to be burped thoroughly and encouraged to latch onto the breast or bottle fully so they don't ingest air. Some babies get air in their stomachs from crying hard.

Miscellaneous

In addition to foods, there are other significant triggers for reflux. Exposure to smoke and airborne allergens can trigger reflux. Exercising or moving a lot on a full stomach is a trigger. Not chewing thoroughly means the

food takes longer to digest. Eating too quickly means that the stomach doesn't have time to stretch to accommodate the meal and can increase reflux episodes. Diapers or waistbands that are too tight can slow digestion and increase reflux. Constipation can slow the whole digestive system and solving this can really help decrease reflux. Using a pacifier or sucking a thumb can be useful because these activities stimulate saliva production and swallowing, which can help wash stomach acid out of the esophagus.

Medications

AS MENTIONED ABOVE, the most common test for GERD is a trial of medication to see whether the symptoms improve, which confirms the diagnosis. Children with GERD are likely to need medication as well as practical

treatments to control their symptoms. Any medication, even over-the-counter formulations, should be administered only under the supervision of the child's doctor. The medications for GERD are just now becoming available in pediatric formulations, and many families will still need help locating, mixing, and carefully measuring adult medications that are compounded for children. These medications may taste awful, and there are many tricks to getting them into a child with minimal trauma.

The dosing of GERD medications for children is not strictly by weight—some children metabolize the medicines particularly slowly or particularly quickly (Rudolph et al., 2001), and the parents need to keep in close contact with the doctor as they find the best dose, brand, and formulation. It may take several tries to find the right medicine and right dose. Trying several medications is common.

Antacids

Antacids (see Table 2) are suitable only for short term use for mild reflux and only with medical supervision. They work very quickly but provide relief only for a very short time. Some formulations cause diarrhea and some cause constipation. Doctors advise that formulations with aspirin or aspirin-like chemicals are not suitable for children.

Acid Reducers

Histamine 2 blockers (see Table 3) are often the first type of medication prescribed for GERD. The dose varies considerably from brand to brand. Over-the-counter and generic versions are available, generally at lower doses than their prescription counterparts. Liquids for children are generally available only by prescription.

Acid Blockers

Proton pump inhibitors (see Table 3) can almost completely eliminate stomach acid

Table 2. Antacids

Brand Name (USA)	Main Ingredient
Tums	Calcium
Maalox	Aluminum and Magnesium
Children's Mylanta	Calcium
Roloids	Calcium and Magnesium
Milk of Magnesia	Magnesium
Preliief	Calcium
Gaviscon	Aluminum and a foaming, barrier agent
Children's Pepto Bismol	Calcium. (Adult Pepto contains bismuth subsalicylate, a chemical similar to aspirin, so doctors advise that this medication should not be used by children)
Alka Seltzer	Contains aspirin, so doctors advise that this medication should not be used by children

Table 3. Commonly Prescribed Medications

Brand Names (USA)	Generic Name/Main Ingredient
Acid Reducers	
Axid	Nizatidine
Pepcid, Mylanta AR plus generics	Famotidine
Tagamet plus generics	Cimetidine
Zantac plus generics	Ranitidine
Acid Blockers	
AcipHex	Rebeprazole
Nexium	Esomeprazole
Prevacid	Lansoprazole
Prilosec and generics	Omeprazole
Protonix	Pantoprazole
Zegerid	Omprazole – immediate release
Barrier Medications	
Carafate	Sulcrafate
Gaviscon	Alginic acid slurry
Motility Medications	
Propulsid	Cisapride – No longer on the market in the USA. Limited availability in special circumstances
Bethanechol	Urecholine
Reglan	Metoclopramide
Motilium	Domperidone – Not available in the USA
Milk of Magnesia	Magnesium
Many brands	Erythromycin
Baclofen	Lioresal

production. Until recently, they were most often used as second line medications but are increasingly being used as first line medications, particularly for children with serious symptoms. These medications are generally available as capsules with time release beads of medication inside. They are extremely difficult to give to children. Manufacturers are starting to sell more child-friendly versions. Be sure the parents you work with are consulting a knowledgeable pharmacist and following instructions closely to avoid spoiling the efficacy of the medication.

Barrier Medications

Physical barriers (see Table 3) protect the esophagus and stomach from damage by providing a coating or barrier from acid exposure. The medication can float on top of stomach contents and may provide a physical barrier to keep acid from backwashing into the esophagus.

Motility Medications

Motility medications or prokinetics (see Table 3) move food through the gastrointestinal tract more effectively and a bit more

quickly by making the muscles work better. These medications can tighten the lower esophageal sphincter muscle. Motility drugs may be used for children with delayed emptying of the stomach and children suspected of aspirating. They are effective only for some children. They have significant side effects including a risk of irreversible side effects.

Stress and Coping

My low point came the day that Katie spilled a bottle of custom-compounded medication that was very expensive and hard to get. I walked out of the house and handed her to a complete stranger. All I knew about the woman was that she had kids and lived in the house on the corner. At that moment, I felt she could take better care of my baby than I could. I couldn't make my baby stop crying, I couldn't get her to gain weight, and nobody in the house had slept in four months. My poor toddler, Chris, was a mess and acting up because he missed his mommy who was always busy with that shrieking baby. I felt like the worst mother in the world. I was worried if I had to drive back the pharmacy, I might drive into a tree—on purpose.

THE PEDIATRIC ADOLESCENT Gastroesophageal Reflux Association warm line has received desperate calls from physicians, PhDs, and pediatricians who say that parenting their child with reflux has been the hardest thing they have done. One veteran New York City police officer/parent said she would rather walk the beat than stay up

Learn More

Pediatric Adolescent Gastroesophageal Reflux (PAGER) Association
www.reflux.org

The association maintains a Web site with 300 information pages and 70,000 searchable postings. The group was formed by parents in 1992 and has a team of trained volunteers.

The Reflux Book, A Parent's Guide to Gastroesophageal Reflux.

By B. Pulsifer-Anderson (2007)
Frederick, MD: Intensive Care Parenting Books
www.refluxbook.com

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

www.naspghan.org/user-assets/ Documents/pdf/PositionPapers/GERD.pdf
Guidelines for Evaluation and Treatment of Gastroesophageal Reflux in Infants and Children.

Listed as "currently in revision." The full guidelines are 31 pages. An 8-page version of

guidelines is also available: www.cdhnf.org/pdf/GERD_8_pg_brochure_031103.pdf

Colic Solved: The Essential Guide to Infant Reflux and the Care of Your Crying, Difficult-to-Soothe Baby.

By B. Vartabedian (2007)
New York: Ballantine Books

A book about reflux written by a pediatric gastroenterologist who has a child with reflux.
www.colicsolved.com

Breastfeeding a Baby with Reflux.

By L. Barmby. (1999). Schaumburg, IL: La Leche League International booklet number 524-24.

Acid Reflux in Infants and Children.

By T. Davenport & M. Davenport. (2006)
Church Hill, MD: SportWork, Inc.
www.makinglifebetter.org.

A list of the many diseases associated with GERD in children can be accessed online at www.wjgnet.com/1007-9327/13/4417.pdf

all night with her screaming baby. Several pediatricians said they knew that babies with reflux are hard to care for, but they didn't realize that it was this bad until they had their own babies with reflux. One mom reported that her parents moved in to help with her baby and a week later her parents hired a full-time nanny to move in as well.

Acknowledging the Parents' Experiences

The most important way professionals can support families dealing with reflux is to acknowledge the extreme stress it causes. A recent study of parents showed that their child's reflux affected the parents' physical health, ability to care for their child, emotional well-being, social life, and family relationships (Crawley, Tolia, Illueca, Barker, & Luo, 2007). A study by the same research group (Luo, Gunasekaran, Illueca, Barker, & Crawley, 2007) documented that some families reported many doctor visits before getting a diagnosis. In that study 40% of working caregivers had to "change employment status" because of their child's GERD and most had significant expenses due to the disease.

Helping the Parents "Read" Their Child

The behavior of children in pain can be very confusing. A baby with reflux may act hungry but be reluctant to eat. You can help the parents understand that the baby's stomach is demanding food but her throat feels raw from reflux and she doesn't want to swallow. Her behavior is confusing because she is frustrated. Any person who is in pain may become less tolerant of frustration and cry more easily when things don't go her way. Reassure parents that their whiny toddler may turn out to be quite independent and cheerful once her pain is gone.

Children with reflux may be in extreme pain. Their parents and other caretakers need to take their pain level into account in all daily interactions. An adult told me that her

reflux as a child had caused extreme family stress. The pediatrician had told her mother to ignore her because she was faking her stomachaches. It drove a permanent wedge between the woman and her mother.

Organizing the Details

The amount of work required by parents of children with GERD can be very overwhelming. Parents may need help recruiting trustworthy assistants to come into the house and help with either the baby or the chores. They may need help organizing the household around the mountains of laundry, special dietary restrictions, the medication and feeding schedule, and the lack of sleep for the whole family. Making charts to help the remember medication and lists of questions for the doctor can be helpful.

Sharpening Observation Skills

Parents are an integral part of the medical team. You can help them to be careful and objective observers of their child's symptoms. Symptom charts are available on www.refluxbook.com, or you can help the parents create a chart that is specific to the symptoms their child experiences. The doctors will find it easier to adjust the dose of the treatment if they can see exactly how many times per day the baby spits up or the toddler wakes up at night crying.

When charting spit-up or vomiting episodes, parents often overestimate how much milk the baby loses. It can help to deliberately pour an ounce of milk onto the floor or a rag so the parents can see the size of the puddle.

Analyzing Patterns and Goals

The day before a child's checkup, it can help to chat with the parents and go over the symptom charts to look for patterns. Are the symptoms worse on days when the baby is constipated? Are the symptoms better on

days when the family is not running errands? Does missing a dose cause a big problem? Make a list of progress notes and questions for the doctor.

You can help the parents develop concrete and measurable goals. Is the goal this month to have the baby eat better, sleep better, cry less? Or is the most urgent goal a 5-hour block of uninterrupted sleep for the mother so she can keep body and soul together while the baby's medicine is being adjusted?

Safety Check

Children who cry a lot, don't eat, and spit up copiously are at higher risk for child abuse (Lee, Barr, Catherine, & Wicks, 2007; Showers, 1994). Even if the parents never take their stress out on the baby, it is quite likely that they will occasionally take it out on each other. Children usually recover from reflux with few memories of those awful months, but parents are often traumatized for years afterward, and their relationship and trust in each other may take a long time to repair. You can help the baby and his parents get through this safely by being sensitive to the anger and drama that stress can create.

Emphasize Successes

Remember to praise the parents for all the patterns they see and coping skills they have developed. They have probably figured out many tricks that work with their baby but they may be fixated on the lingering problems and forget the progress they have made. ♡

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