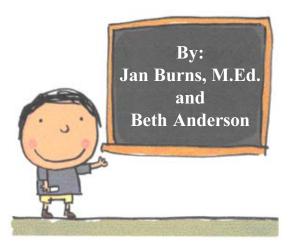
Going to School With Acid Reflux:

A GUIDE FOR PARENTS







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© 2003 PAGER Association By Jan Burns, M.Ed. and Beth Anderson Pediatric/Adolescent Gastroesophageal Reflux Association Buckeystown, MD, USA www.reflux.org

Resources:

Pediatric Gastroesophageal Reflux:

PAGER, Pediatric/Adolescent Gastroesophageal Reflux Association, P.O.Box 486, Buckeystown, MD 21717-0486, 301-601-9541, www.reflux.org, gergroup@aol.com.

PAGER's mission is to: (1) gather and disseminate information on pediatric gastroesophageal reflux (GER) and related disorders; (2) provide educational and emotional support to patients with GER, their families, and professionals; (3) promote awareness of GER within both the medical community and the general public; and (4) to promote research into the causes, treatments and eventual cure for pediatric GER.

Section 504 Plans:

Section 504 plan: Go to www.wrightslaw.com. Link to articles: Advocating for your child: Getting Started, and The Parent Advocate: First Steps.

Emergency Forms:

Consent form, Emergency Information Form for Children with Special Needs, www.acep.org

Many thanks to the following parents who contributed to this pamphlet: Tami Peavy, Annette Pic, Laura Barmby

INTRODUCTION

Parents may feel apprehensive about sending their child with acid reflux to school. As parents, we know how to identify and manage reflux symptoms at home. It may seem scary to



have someone else manage medical care and special feeding needs in our absence. It is our responsibility to share our knowledge about acid reflux and how it impacts our children in so many subtle ways including: eating, behavior,

learning, endurance and self-image. Most likely, the school staff will feel a great sense of relief about their ability to understand the disease and how to manage it. Many parents feel less apprehensive about sending their child to school once they have met with the school staff and explained the situation.

Most children are eager to go to school, blend in and participate fully in all activities. A positive, "can do" attitude about going to school with acid reflux sets the tone for the school staff as well as for your child.

Pediatric Gastroesophageal Reflux Disease: Information for Teachers

What is Gastroesophageal Reflux Disease (GERD)? Gastroesophageal Reflux Disease or GERD is the abnormal backwashing of stomach acid/contents into the esophagus. It is a common chronic illness with symptoms ranging from mild to life threatening. Symptoms may be controlled by a combination of treatments including: diet, medication and positioning.

Common Reflux Symptoms:

Note: Symptoms may vary from day to day, increase with illness or after eating certain foods.

Vomiting/regurgitation	Bad Breath/Tooth enamel erosion
Pain in stomach, chest, throat	Poor sleep
Poor weight gain/weight loss	Burps/hiccups
Asthma, pneumonia, bronchitis	Ear Infections
Gagging, choking	Cough, hoarse voice, throat clearing
Picky eater/food intolerances	Sinus infections/runny nose

Diet:

Food that commonly trigger reflux symptoms include: dairy, tomatoes, citrus, high fat foods, spicy foods. Some children have food allergies/intolerances in addition to GERD. Common food allergies/intolerances include: wheat, soy, dairy, and nuts.

Environmental modifications:

- Limit physical activity after meals.
- Frequent, small meals and snacks. Frequent sips of water.
- Extra time to eat slowly and carefully.
- Access to the restroom.
- Access to medications during the school day.

Attention and Learning:

Some children with reflux have difficulty with attention, behavior and learning due to dehydration, nutritional problems and pain from acid reflux. was not followed and she endured standardized testing without access to her snack and water bottle. When the test results came back showing poor performance in all areas, I was really worried. Was she significantly delayed in her learning or was her frequent snacking that important for her to demonstrate her abilities? At that point, I requested testing under a Section 504 plan. She retested at or above age level in all areas when she was allowed to have snacks and water, which proves that her reflux was affecting her grades. We developed a Section 504 plan for her due to her medical needs under "Other Health Impaired". Now the school informs me when she is being tested and monitors her access to snacks."

"The school principal asked me to go on every field trip so that I can help my daughter eat and use the restroom as needed."

" My son has a severe allergy to soy, a common ingredient in many foods. I was concerned that the staff of his preschool or a substitute would give him a food containing soy by accident. I made a sign with a picture of my son that reads, " My name is Sam. I am very allergic to soy. Please read ALL package labels before giving me my snack. I will get very sick if I eat soy and may have trouble breathing. If I ever vomit or have trouble breathing after a meal, call 911."

From the mother of a teen with reflux:

" Many schools have a policy that you can't participate in an after school activity on days you have been absent. The school administration has to be made to understand how important it is for GERD kids to be included in the school loop as much as possible. Due to the absences our kids endure from GERD, it is a real challenge to stay connected to the school social scene. If our kids feel well enough to make an after school activity, they should be allowed to do so regardless of whether or not they were in attendance."

PARENT STORIES:

"The teacher thought Rob was trying to be disruptive by coughing and clearing his throat too much. Once she realized that was part of his reflux, she didn't give him a hard time again."

"When I talk to his teacher, I explain that although reflux is uncomfortable, this is unfortunately "normal" for him."

"I am slowly learning how much control over reflux I have at home and how it is important to communicate that information to the school."

"I felt less anxious about sending my daughter to school after I spoke with the school nurse and the teacher."

"As a parent I wanted my child to be as normal as possible so I did not go into much detail with my child's kindergarten teacher. I simply stated she had reflux and asthma. I quickly learned this was not a smart approach. The reality is my child is different and she has some special needs. Within the first two months of school (at my child's request due to discomfort and pain) I made special arrangements for my child to take rest time on a wedge instead of a flat mat I also send in a special snack which is eaten around 11am to prevent "blood sugar crash". And lastly I have made arrangements for her to use the restroom more frequently and for longer durations. I was very surprised to see how receptive both the nurse and the teacher were to the requests. In the end I learned what really matters is that my child now comes home from school happy, pleasant and without intense stomach and chest pain."

"My daughter had a nursing plan for attending elementary school, including a note from her gastroenterologist specifying that she could have food and drinks as needed during the day. The plan

Question: What should I tell the teacher?

Before your child begins school, it may be helpful to meet with the school staff including: the principal, teacher(s), school nurse and all classroom helpers (teacher's aide, lunch monitor, etc). It can be intimidating to have a meeting with the school staff. Be sure to bring a friend or relative to help you take notes, ask questions and provide important information. Provide a simple, plain English explanation of acid reflux and how it affects your child. For example, you could say, "Joey has acid reflux which causes stomach acid and food to go up his esophagus into his throat. His reflux is worse just after lunch and you may notice that he has a lot of throat clearing and burps. We find that he does best at home if we give him a lot of time to eat so he can take small bites and eat slowly and carefully". You may want to prepare a short written statement or letter with the following information: child's name, description of reflux, symptoms, and ways to decrease reflux symptoms. See the resource section for a sample letter.

Question: What if my child needs medication for reflux during school?

Before school begins, visit the school and identify a member of the staff who will administer medication. In most cases, the nurse or classroom teacher may be trained to administer medication. The school will require a doctor's note or a special form to administer prescription medications. You will need to provide medication in the original packaging with your child's name and the dose clearly marked on the container. Your pharmacist can provide you with an empty, labeled bottle for school.

If possible, contact the school one month before school starts so there is ample time to fill out any necessary forms and obtain a doctors signature. Again, provide a written statement with the following information: Name of medication, dosage, dosing instructions, name of prescribing doctor and a statement giving permission to administer the medication. Provide an ample supply of all medications at school and replenish the supplies on a regular basis. In rare cases, an older child/teen will be given permission to carry medication such as Tums to use as needed. It is likely a physician's note will be needed as well as permission from the school principal and nurse.

Dear Teachers,

I wanted to tell you a few things about my daughter Rebecca. She has a medical condition called **Pediatric Gastroesophageal Reflux Disease**, also know as reflux or heartburn. Stomach acid backs up into the esophagus, causing pain and discomfort, burping and an assortment of other symptoms. Rebecca has a severe form of the disease, requiring surgery and a gastrostomy tube (feeding tube) for supplemental feeding when she is unable to eat by mouth. I would be happy to discuss the disease with you if you have further questions or concerns.

Triggers: Reflux is a chronic illness and symptoms can vary greatly. Sometimes, symptoms improve for days or weeks at a time, only to return unexpectedly.

Rebecca's Triggers:

 Illness: Any kind of illness causes Rebecca to stop taking food by mouth and she needs to gradually re-introduce food and fluids by mouth. This can take several days to a week, depending on the severity of the illness. The stomach flu usually requires a 3-day hospital stay for IV fluids.

- 2. Foods: Certain foods trigger reflux symptoms: soda, nuts, dairy products are the biggest triggers. However, simply drinking a big glass of water all at once triggers her reflux.
- 3. Eating too much or too rapidly causes burping and a big tummy ache.

Things that help Rebecca control her reflux:

At home, Rebecca takes several medications and always sleeps with her head elevated to control her reflux.

During the day she needs:

- 1. Frequent, small meals or snacks, approximately every 2-3 hours.
- 2. Time to eat and drink slowly to aid proper digestion.
- 3. Unrestricted access to the bathroom.
- 4. Rebecca needs to go to the head of the lunch line so she has more time to eat.
- 5. During lunch, Rebecca needs to continue eating if she wishes while the other children recycle.

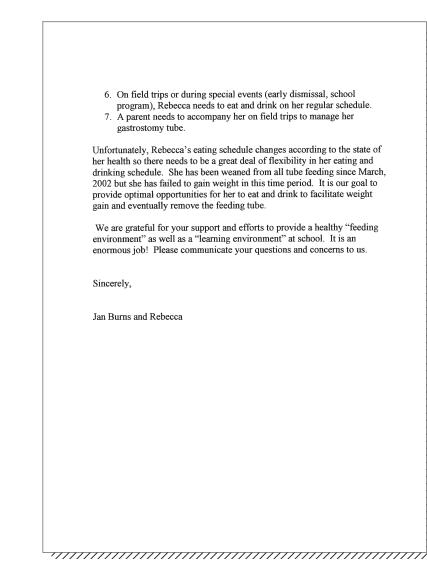
A FINAL WORD:

Children with acid reflux have already learned a great deal about life. They have endured pain and discomfort and learned to get out of bed every morning, eager to start the day. They embrace life fully and that includes slinging a backpack over their shoulder and heading off to school. While their backpack may contain special foods, cans of Pediasure, extensive notes from mommy and a feeding pump, we know that for the most part they just blend into the crowd. But it didn't just happen that way. As parents, we have helped our children with acid reflux have a positive attitude and sought aggressive treatment so they can function and enjoy life to its fullest After all of the planning and preparation, we should feel proud of our children and proud of ourselves for helping them to go to school.



temporary basis, but you could run into serious trouble if there is a change of teachers, administrative personnel or when your child moves on to the next school. Parents need to know their rights and be an advocate for their child. Many parents of children with reflux are used to being advocates and have been fully trained "on the job". Parents may want to visit www.wrightslaw.com for information on Section 504 plans. Be sure to read the articles titled, "Advocating for your Child: Getting Started." and, "The Parent Advocate: First Steps".





Dear Teachers,

I wanted to tell you a few things about my daughter Jenna Burns. She has a medical condition called **Pediatric Gastroesophageal Reflux Disease**, also known as reflux or heartburn. Stomach acid backs up into the esophagus, causing pain and discomfort, burping and an assortment of other symptoms. Jenna has daily symptoms that are controlled by diet and medication. I would be happy to discuss the disease with you if you have further questions or concerns.

Triggers: Reflux is a chronic illness and symptoms can vary greatly. Sometimes, symptoms improve for days or weeks at a time, only to return unexpectedly.

Jenna's triggers include: eating a large meal, eating too fast, and ingesting dairy products.

Things that help Jenna control her reflux:

At home, Jenna takes several medications and always sleeps with her head elevated to control her reflux.

During the day she needs:

- 1. Frequent, small meals, snacks and drinks.
- 2. Time to eat and drink slowly to aid proper digestion.
- 3. Unrestricted access to the bathroom.

A snack letter from her pediatric gastroenterologist is attached.

We are grateful for your support and efforts to provide a healthy "eating environment" as well as a learning environment at school. It is an enormous job! Please communicate any questions and concerns to us.

Sincerely,

Jan Burns and Jenna

Rebecca .		001.27	School 7	Amold Elemi
ate of Birth 7/29/94	Grade 2		Meeting i	Date 416/02
Problem(s) Identified	Intervention(s)	Implementor(s)	Time Line	Specific Result(s)
Left ear	-provide preferential Seating,	Rebecca	on-going	To be monitored.
Conductive hearing loss-mild	-repeat instructions as needed	teachers		
tympanoplasty	- Check for understanding			
adrenal insufficiency	- monitor for signs of hypoglycernia and dehydration collector upwerd	teachers and Rebucca	ongoin	
1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 -	- Encourage Retecca + take advantage of "wait time" Checkwork	- Kebecca	on-going	to be menitored
	for completeness + accur re-read the directions,	ncy,		
	reference the text when		<u>`</u>	
	- Testing may be opted to be postponed or mad	(due to heard lified as is possible	h reisins) on going	Teachers Parent
rticipants in Plan Development: <u>Ros</u> int Names and Positions) Var	compry in an		Carol, Beth in	<u>~</u>

Result of Review: Successful/continue implementation Revise strategies (see new plan) Obtain additional information Refer to IEP Team

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Rebecca	SIF	04		School	tmold t	Tementar
7/29/94	Grade 3			Meeting C	4/16/0z	10/16/02
Problem(s) Identified	Intervention(s)	Implementor(s)	Time	Line	S	pecific Result(s)
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GERD	scheduled time every day - go to head of line	-teachers ar cafeteria s as remina	taff			
	for lunch purchase, recycle last.					
	-mother will attend field trips					
	- have access to bathroom as often as					
	needed - access to water as					
	often as needed - allow make up work as needed	-				
sthma	- Albuterol by inhalor or	Rebecca	on- goin	5		
	nebulizer as needed					
pants in Plan Development:	ssemany -		Caro	1		
lames and Positions)	beth		Jan		-	

Des / of Devices 🔲 Suppose full continue implementation 👘 Revise strateriles (see new plan) 📄 Obtain additional information 👘 Refer to IEP Team

However, there is a provision in the law to ensure equal access and opportunity to education for children with a medical condition, even in the absence of a disability if they have a "health impairment" that can impact their school performance. For instance, if a child has acid reflux (medical condition) that is so severe that the child is weak or irritable and cannot focus on learning, he/she may need special accommodations under a Section 504 plan to ensure equal opportunity to receive an education. Other reasons may include: poor endurance, frequent absences due to illnesses or medical treatment, poor sleep leading to daytime fatigue, and time for medical treatments such as tube feedings, snacks and medications. Special accommodations need to be identified that will allow the child to participate in school without being penalized due to the medical condition. For instance, if a child needs to have a tube feeding every day during math class, the child would probably receive a failing grade due to missed assignments and poor test scores. With a Section 504 plan, the school and the family would develop a plan for providing the tube feeding and providing math instruction. Remember, many children with acid reflux have a school-nursing plan in place to specify medical needs and school/classroom accommodations. A Section 504 plan is probably warranted if the child has complex medical needs or if the school has not been able to provide care and treatment under a nursing plan.

Question: *How do I set up a Section 504 plan for my child?*

It is likely that the school will not offer information about a Section 504 plan and you will have to seek information from the school principal, the nurse or the school system's special education/504 compliance officer. The reality is, the Section 504 plan obligates the school to implement the school action plan. Failure to do so is a violation of your child's civil right and is punishable by law. Some parents have reported that the school staff offered a school based plan rather than a Section 504 plan. This may be fine on a

Question: *My child needs special care during the day. Who will help him/her?*

During the planning meeting with the school staff, one or more staff members should be identified to assist your child during the school day. Day care centers and preschools rarely have a nurse on duty so it is usually the responsibility of the teacher or school director to administer medication and supervise a special diet in a pre-school. Many elementary schools have a nurse or nurse aide available. Regardless of who is chosen, it is vital to have a back up plan in case the nurse or teacher is absent. Often, parents come to school for a few days to work with the staff until they feel comfortable providing care for your child.

A school-nursing plan may be developed to describe the medical condition and medical plan for school. The nursing plan describes special treatments and emergency protocols and clearly identifies who is responsible for providing care. Regardless of who oversees your child's care, be sure you have identified someone on the school staff who knows what to do in your absence and how to contact you or another family member or friend in case of a question or concern.

Question: What should I write on the emergency forms?

Most schools and day care centers have their own medical history forms and consent forms for emergencies. The forms typically ask for generic information such as diagnosis, doctors name, immunization info and who to contact in case of illness or injury. It may be necessary to provide a sheet with additional information or use one of the more detailed medical forms from the resource section. Fill out the forms well before the first day of school so that the school staff has ample time to review and plan. In some cases, it may be necessary obtain medical documents or a statement from the pediatrician or gastroenterologist regarding diagnosis, treatment and emergency protocols. Some parents provide specific information such as: name of the doctor or

and Child's Medical Information
In presenting my son/daughter for diagnosis and treatment
Name:forforforforforDaughter
of
I hereby acknowledge that no guarantees have been made to me as to the effect of such examinations or treatment on my child's condition.
I have read this form and certify that I understand its contents.
We/I hereby give our (my) consent to
who will be caring for our (my) child (Name of Child)
for the period to to to to to arrange for routine or emergency medical/dental care and treatment necessary to preserve the health of our (my) child.
We/I acknowledge that we are (I am) responsible for all reasonable charges in connection with care and treatment rendered during this period.

Medical/Surgical Care/Emergency Treatment

Consent for

Other children benefit from eating slowly as well as bringing food from home for meals and special celebrations (if the child is on a special diet). Access to the restroom, water fountain or a water bottle may be necessary. Some children have a permanent pass for the nurse and restroom. Remember to discuss plans ahead of time for fieldtrips, half days and other days when the schedule may be modified. A written plan in the notes for a substitute teacher can help the child and the teacher enormously.

Question: Does reflux affect learning?

Parents and teachers have reported that a child who is in pain from reflux is less able to concentrate on schoolwork. Children with chronic, daily symptoms may be prone to dehydration, low blood sugar, fatigue and malnutrition, leading to poor performance. Some parents and teachers report inconsistent school performance, acting out behavior, and low frustration tolerance.



Question: *What about the child with complex medical issues?*

A few children with reflux have severe, daily reflux symptoms that interfere with learning and school attendance. In addition, these children may have complications from their reflux including: asthma, recurrent illnesses, gastrostomy tubes, nasograstric tubes and feeding pumps. Children with chronic, complex medical needs due to reflux that adversely affects learning may need a Section 504 plan to plan and coordinate special accommodations at school.

Question: *What is a section 504 plan?*

Section 504 is part of a United States civil right law to ensure disabled children and adults have equal access to school/work.

Question: What can make reflux worse at school?

Every child is different. However, many children with acid reflux report pain and discomfort from:

• Engaging in physical activity after a meal. For example, lunch followed by recess or PE.



• Schedule-eating too late or too early, getting too hungry and then experiencing stomach pain from eating too fast. Often, the school lunch period is not long enough to buy lunch, chew carefully, and eat slowly.

- Menu: school lunches often contain foods that are irritants to children with reflux: fried foods, high fat content, dairy products, and no alternative to milk as the beverage served.
- Restricted access to water and snacks, leading to low blood sugar, dehydration, discomfort.
- Restricted access to the restroom leading to bloating, pain and discomfort.
- Limited access to medication.
- Changes in meal schedules due to field trips, special events.
- Eating foods that trigger reflux symptoms, especially holiday celebrations, birthday celebrations, etc.

Question: *What accommodations are needed to help my child with reflux at school?*

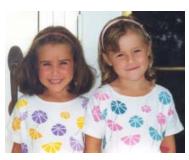
Parents, teachers and students will need to work together to figure out an individual plan for managing reflux at school. Some children need frequent, small meals or access to foods and drinks throughout the day rather than a pre-determined lunch period.

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No: Surgeon: No: Orthopedist: alth insurance carrier: Orthoredist: Date of last tetanus booster: Date of last tetanus booster: no:: Medicines child is taking: Mohter. Furher or Legal Guardian Medicines child is taking:	Address:	Pediatrician:
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Moher, Father or Legal Guardian	Agreement no.:	
	Signature: Mother, Futher or Legal Guardian	Date:
	Witness:	Date:

specialist who coordinates care, name of hospital or regional medical center, names of all specialists, a current list of all medications the child uses, allergies, special instructions, current weight, height and other baseline information.

All emergency forms require parents to identify a person to contact if the parents cannot be reached. While it is likely you will be contacted if your child becomes ill at school, it is important to have a back up plan. Try to identify a person such as a relative, neighbor or friend who is familiar to your child and also familiar with his/her health condition. Some parents need to discussion reflux with their emergency contact and provide them with a list of phone numbers so they can reach you. Always update the information on a regular basis. Remember, in a true emergency, the school will obtain medical care for your child without delay and contact you immediately.

Question: What should we tell the other students in his/her class about reflux?



Preschool children are curious about other children and quite accepting of individual differences. A simple explanation such as, "Laura gets tummy aches very easily so she needs to have special food/medicine." is usually enough to satisfy a preschooler.

Older children are often selfconscious about their differences

and may be embarrassed about having to explain reflux to their peers. It may be best to consult the older children and find out what they want their peers to know. You may want to help your child rehearse a short statement regarding reflux to explain their condition to peers. Kids may say, "I have reflux so my stomach hurts after I eat", "My doctor said I need to stay away from certain foods." "Certain foods don't agree with me.", "My stomach makes a lot of burps because I have reflux". Some children have a code or signal to alert the teacher (about pain/ discomfort, nurse, restroom) without revealing the situation to the entire class. Older children may deny pain and special accommodations in an attempt to blend in with their peers. Some teens have a standard, humorous response to an inquiry about acid reflux. The reality is, most children with acid reflex blend in at school and may go unnoticed by peers and staff alike.

Question: Some of the kids have been teasing my son because he makes funny throat clearing noises and belches loudly after lunch. How should I handle this?

Other children often take their clues from the child with medical



problems. If your child isn't embarrassed and doesn't get upset by teasing, it probably won't become an issue.

Some parent's help their children think of a catchy or humorous phrase to use when confronted by a child making an

unkind remark. If the problem persists or is overwhelming for the child to deal with, speak with the teacher, guidance counselor, principal or physician.

One teen has a special burping rhyme:

Pardon me for being rude. It was not me, it was my food. It got so lonely down below It just popped up to say hello!

Quote from the movie, Jimmy Neutron, Boy Genius:

After burping loudly...

"Glad it was from the attic and not the basement!"

Last name:

Emergency Inio	Emergency Information Form for Children With Special Needs	Children With Sp	ecial Nee	cis l
American College of Emergency Physicians*	American Acarmy	Date form Re completed By Whom	Revised Initials Revised Initials	
Name:	D	Birth date: N	Nickname:	
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Parent/Guardian:		Emergency Contact Names & Relationship:	ship:	
Signature/Consent*:	2			
Primary Language:	C	Phone Number(s):		
Physicians:	S			
Primary care physician:	10	Emergency Phone:		
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*Consent for release of this form to health care providers