



Kids with Tubes News

A newsletter connecting parents and caregivers of
tube-fed children

Letter from the Editors

Kids with Tubes is pleased to be publishing this second issue of *Kids with Tubes News*. The response to our first issue, "The Decision to Place a Tube" (March 2000), was very encouraging. Families told us it captured the struggles and emotions involved in their own decision. Professionals commented that the content, especially the glossary, would become a wonderful resource for sharing with others. All agreed that the stories were positive, yet realistic.

Thanks to the generosity of the Early Intervention Parent Leadership Project, there was a second printing of the newsletter. It was shared with each Early Intervention program in the state of Massachusetts, as well as Department of Public Health case managers and specialty service providers. We have also published a slightly modified version of the newsletter on our website, www.kidswithtubes.org. This allows us to share the newsletter outside our membership area of New England and make it available to anyone in the world who may find it useful.

As we all know, managing daily life with a tube-fed child can be challenging and stressful, not to mention frustrating and messy! In this issue of *Kids with Tubes News*, we have collected a variety of stories, tips, and thoughts on how we cope. In August, we sent a letter to each member family of Kids with Tubes, requesting their input. We suggested a variety of topics on which they could write. Interestingly, the majority of the contributions are in the area of the child's own perceptions and how they manage socially.

In addition to the contributions from families, we asked several professionals to write on topics that pertain to our daily lives. These include suggestions for talking with your child about his or her feeding tube, coping with granulation tissue, easing communication with your insurance provider by working with a case manager, managing tube feedings, and obtaining tube feeding supplies. Thanks to Lori Parker-Hartigan, Donna Fruman, Deborah Pfister and Pam Sawyer for their articles on these topics.

Kids with Tubes is grateful to all those who have contributed. For reasons of privacy, we have removed all children's names from the texts.

While some of the contributions have been modified for ease of reading, we attempted to retain the content as well as the personal story telling style of the writer. As we edited this newsletter, we had the image of parents and caregivers sitting informally together, exchanging tips and tales of life with a tube-fed child. We hope you enjoy joining this conversation. We always welcome your feedback and encourage you to participate in future newsletters.

Sincerely,
Jill Crisman
Irene Walborsky
Sue Wolff

Fall 2000

Daily Life with a Tube-fed Child

Our shared principles:

- *Each child with a feeding tube is unique – what works for one child and family may not work for another.*
- *Always check with your child's doctor(s) and/or therapist(s) before using any information presented in this newsletter for your child's treatment or care.*
- *All information that is learned through any Kids with Tubes forum is to be treated with complete respect and confidentiality.*
- *Some children will outgrow the need for a feeding tube, others will have a tube for their life-time; we seek to support all parents and caregivers of tube-fed children, whatever their experience will be.*



Managing the Tube...

About two weeks after our five-year-old daughter's G-tube insertion, she hopped over our baby gate and screamed. The dangling G-tube had caught on the gate as she went over. The tube wasn't pulled out (thank goodness), but the cap had come undone and spilled stomach contents all over the floor. Understandably, this horrified her. I quickly and cheerfully cleaned it up but it really gave me a scare! So, after that, I never allowed the tube to dangle even for a few minutes. I always pinned it to the inside of her shirt.

To prevent leaking from the G-tube cap, I place a long piece of fabric/silk tape over each closed port to prevent the caps from getting caught and opening while playing. Then, I fold a 4 or 5 inch piece of the same tape around the tube just at the base of the ports. Sticking the sticky ends together creates a non-sticky tab. Using a newborn cotton infant mitten, I place the end of the G-tube into the mitten. Then, I pierce the edge of the mitten and the edge of the tab with a diaper pin. I pin this to the inside of the child's shirt or dress, a few inches higher than the stoma. This elevation may help minimize leaking as well.

When he first became mobile, I switched from the pump to a syringe (with plunger) and slowly gave the feeding while he was doing whatever he might like (play, crawl, etc.). I felt that this allowed him more freedom than he would have had if I did gravity or pump feeds.

At bedtime, we use 1" tape to tape the portholes and connection of tubing so the tubing is not as easy to become disconnected when our child moves in the nighttime. We also use underpads to line the child's bed. It is not fun

cleaning a bed that is saturated in formula!

When my three-year-old son got his first tube in June, I expected it to last approximately four months. Instead, in only three months, he's had four! On two separate occasions he has bitten off and swallowed the large rubber stopper of his tube. On another occasion he punctured the port with his teeth. Did I happen to mention that my son is extremely oral! Between the wear and tear of eleven hourly boluses, venting and my son's oral fixation, we'll be sure to surpass our insurance's limit of three replacement tubes per year. Obviously they hadn't met my son when that rule was made. I guess just as sometimes rules are meant to be broken, so are G-tubes!

My son was on continuous feeds for quite a while. Nighttime feeds were frequently accompanied by gagging and vomiting, wet bedclothes, disturbed sleep for everyone, as well as morning coughing and vomiting, absence of appetite and intolerance of morning tube feeds, etc. Gradually I shifted away from nighttime to daytime feeds. These were essentially continuous at first, but gradually I was able to move toward small (5-10-20 cc. at a time) "bolus-feeds." As I transitioned to bolus, I transitioned away from the pump to using a syringe. Gradually, as he got older and bigger and more upright and more mobile, the "boluses" became larger (now, at age 5, they are many ounces!). As I became able to reduce the hours of nighttime feeds, the associated problems decreased.

As our son became able to roll over, we were very concerned he would strangle himself in his crib. We

would get four foot extension tubing from our supply company to make the tubing from his pump longer. Then we would run the tubing down his pajamas, through the foot opening, and through the rails near the mattress of his crib. This would make sure that there was no tubing hanging from the top of the crib. It also helped in that he didn't kink the lines too often in the middle of the night.

Many feeding pumps can be set up in *interval timer* mode. This feature is useful to avoid getting up in the middle of the night. For example, if you want to give your child a bolus feeding lasting about 1 hour and you want to repeat this every 3 hours, you can set this up in the interval timer mode on your pump. In the middle of the night, it will turn on, give the bolus, then the pump will go into a sleep mode. The pump will then wake up in three hours and give the next bolus. This will repeat until you wake in the morning and turn off the pump. Another example how this is useful, if you start an overnight continuous feeding at 10 PM and you want it to stop at 5 AM, you can set your pump to give a 7 hour feeding (at the rate that you set) and have it repeat the feeding in 12 hours. This way the pump will go into a sleep mode at 5 AM, and you don't have to get up to turn it off. When you wake later in the morning, you can easily turn off the pump before the 12 hour interval has passed.

Granulation tissue was a problem during the first years. I found that all the interventions I tried irritated it. Ultimately, when it would flare up, daily soaks in the bathtub (no soap) helped it to heal. At times a small application of Calendula ointment was also useful.

Coping with Granulation Tissue...

Granulation tissue is the raised, sometimes painful, red tissue which can develop at the margins of the gastric stoma (the surgical hole into which the gastrostomy tube, or G-tube, is placed). Granulation tissue can bleed and promote leakage of stomach contents through the stoma onto the surrounding skin.

One factor that promotes the development of granulation tissue is the ongoing friction between the G-tube itself and the skin. This friction can be caused by a poorly fitting G-tube or one that is not stable (i.e. rocks back and forth in the stoma.) To prevent the formation of granulation tissue, it is important that your child's

tube is well-stabilized. Means of accomplishing this include making sure the external bolster of the G-tube gently sits against the skin without leaving any marks or indentations on the skin, or ensuring your child's skin level tube (MIC-Key/Button) is properly fit. If your child has a skin level device, do not leave the feeding adapter on, as this will cause drag on the tube and make it unstable.

Another factor that may contribute to the formation of granulation tissue is improper skin care. Generally speaking, the G-tube stoma area should be left open to air and cleaned only with soap and water during bath time. Ongoing use of hydrogen peroxide may contribute to the development of

granulation tissue.

Once granulation tissue is present, it can be tough to eliminate. First, make sure your child's tube is stabilized and you are caring for the skin properly. Some clinicians may recommend the application of silver nitrate solution to help shrink the tissue. Others may try a course of steroid cream for a short period of time to eliminate it. It is very important to meet with your clinician and have the stoma area evaluated so the best plan for treating and preventing the formation of granulation tissue can be made.

Lori Parker-Hartigan, R.N.
Children's Hospital, Boston, MA

Travel...

There is only one good thing about feeding a baby via G-tube and that is that I can drive AND feed the baby at the same time! Try doing that while nursing!

We send all of our medical supplies early to the hotel i.e. formula, feeding tubes, bags, syringes, and underpads. That leaves us with a lot less to carry on the plane.

We took our daughter for an overnight stay at an inn in New Hampshire. I had brought along a brand new pair of feetsy pajamas for her. As bedtime came, I set up her pump and dressed her for bed. Oops! I had forgotten to cut a little access hole in the PJ for her tube. And, of course, I had no scissors. So, dressed in her PJ, I carried her out to the innkeeper's desk and asked for a pair of scissors. As he handed them

to me, he said, "Need to cut the tags off?" I didn't know just how to respond as I positioned the scissors right at her belly.

When we're overnight away from home, we set the pump on a chair. We hang the bag on a hanger that we hook on the back of the chair, or on a lamp nearby.

Last February we took a family vacation with a car trip to California. We had a van, so there was plenty of room for a three day trip each way. We drove one and a half days and then stopped at a hotel for a night of rest. In the van, the feeding pump ran on battery power as our daughter slept in her car seat. Then, we recharged the battery while at the hotel.

Last Christmas, we forgot our son's pump (and pacifiers and pajamas...)

when we were visiting my in-laws in the middle of nowhere. We discovered that we left the pump behind at 11 PM when everything was closed. Early the next morning, we called every medical supply company listed in the phone book and found one that rented the same pump that we used. They loaned it to us for four days until we got home and we mailed them back their pump. We offered to pay but they wouldn't take any money — I don't think that they even knew how to charge us.

When flying with a PET pump, I find the alarm rings frequently. It helps if the reservoir in the tubing is filled higher than usual (however, be sure to leave some air space) so when the plane tilts, there is always formula in the reservoir. If you hold the reservoir horizontally when you prime the tubing, you can control how much it fills.



A Child's Perspective...

Our five-year-old daughter who has cystic fibrosis called her G-tube her “teletubie” (pronounced tele too-bee)! It really provided some needed levity and made her teletubie a bit more familiar, less foreign, and even a little fun. Now that she has a MIC-Key button – it’s her “tummy button”. But, now, she is so used to having it, the name isn’t a big deal anymore.

Our kindergartner really enjoys the book Just Like Me by Lori Mitchell. It discusses how in spite of our differences from one another, we’re all alike in the ways that matter.

When my daughter was a baby, I often wondered what her experiences would be when other kids began noticing her button. Would she feel oddly different? Would she know what to say? Well, one day after pre-school, she said to me “Mommy, Andrew asked me what my button was.” “Really?” I said – dying to hear more. “What did you tell him?” I casually asked. “I said it’s so my mom can attach a tube and give me a tube feeding”. I couldn’t have said it more clearly myself. Andrew was satisfied.

Our tube-fed daughter’s brother helps with the tube when he can. We never hide it from him. He and his sister have taken baths together. This is a good way to show the tube to a sibling. He is also asked if he would like to help set up her tube from time to time. She gets a lot of attention at night, and he sometimes gets jealous or sad. I try to make up the time on the weekends with him.

Our daughter’s cousins and friends of the family all know she gets fed differently because of the way she was born. We don’t make a big deal of it. She doesn’t really ask any questions about it. It might be that she’s too young, or it is just a way of life for her and she doesn’t know any different. She’s the first one to yell out “Dose Delivered” when her pump beeps. She started saying this when she was 2 ½! She also will ask, “Is it a kink, Mommy?”

A revelation from a six-year-old about his tube-fed brother, and I quote, "Hey, I just realized something. Guys WITH feeding tubes get MORE attention than guys who DONT!"

I made a special “Doctor Book”. I use it to anticipate medical visits and to help my son know his own life story. When he was young, I brought a camera with us to the hospital and medical appointments. I took photos of him, along with various medical equipment, as well as with some of the health care providers. I also took pictures of the fun things—garden, giant bagels, parking lot, etc.! I was sure to include Mom, Dad and other special people in photos of the difficult times, such as being in the Intensive Care Unit or undergoing uncomfortable tests. My hope is that when he sees these pictures, the love of the people in the photos will accompany that situation.

We put MIC-Key buttons into a stuffed animal and a doll. These have been used in play and for showing other children how the button and extension tubing work.

Placement of a feeding tube in your child is a critical decision for you as a parent to make. Usually every means of feeding orally is tried and exhausted before the idea of a feeding tube is broached. Nourishing your child orally is perceived to be the most fundamental of parental skills and using an artificial means to accomplish this act may leave parents feeling inadequate and overwhelmed. Therefore it is understandable that discussion of the tube with family members, friends and other parents may be painful. Being selective in whom one chooses to share such intimate details may be appropriate.

But such selectivity is not possible with your child. As children grow in stature and understanding, they may question their differences. Children are aware of others from a very early age and, whether they can verbalize or not, may wonder why they have a tube in their abdomen and their siblings, family, friends do not.

Being open and honest with your child from the beginning of your relationship together is a sturdy platform from which both of you can grow. Explaining to your child in an age appropriate manner as to why the tube is necessary gives a base from which he or she can ask other questions. Your comfort with the tube will be transferred to your child through your words and actions so it is important that parents be given the opportunity to ask their own questions and deal with their own fears by talking with friends, clergy or other professionals. Honesty empowers your child to feel loved and accepted for who he or she is, while concurrently giving parents the opportunity to express unconditional love. Honesty is a gift from which the whole family can benefit.

Pam Sawyer, R.N.
Minuteman Early Intervention

Helping Others Understand...

One day my two-year-old and I were visiting a friend with a child a bit older. We were having lunch. When I began the tube feed, the older child asked what I was doing, and his mom said I was giving medicine. I knew immediately this was not the answer I wanted my son to hear. I realized even my dearest friends did not know how to answer these questions, and I needed to teach them. I recall struggling to figure out what-in-the-world to say. After tying myself into knots, wishing I could spare my son and myself his problems, I knew the Truth was what I needed to say! I needed to have the story in words that made sense to me and were what I wanted my son to know about himself. Then I could answer such questions and teach my friends to do so too.

When he began attending summer camp and then receiving tube feeds at his nursery school, he was worried about the reactions and questions people would have about his G-tube. I wrote a letter, incorporating the story we tell, and I helped our son create an equivalent letter for his friends. Parents and teachers have found the letter helpful, as have family and friends. My son often asks me to “give the letter” to someone. Here are modified versions of the letters:

Dear friends,

In the spirit of the saying “*It takes a village to raise a child*”, we write this rather personal letter. Thank you in advance for the respect with which you receive it.

As swimming weather is now here, your children may comment or ask about Rob. As some of you know, Rob was born with Congenital Heart Disease and has a G-tube (Gastrostomy tube)—a tube surgically placed into the stomach that allows nutritional supplements to be given, when one cannot eat or drink enough orally. He may need supplemental nutrition following lunch—an extra drink and possibly supplements through his tube. Your children will probably be curious.

As we have explained to Rob, people are usually curious about, or even confused by something they have not seen before, and G-tubes are unusual. If the grown-ups understand, they can help answer kids’ questions. Here are some ideas for answering questions:

“That is Rob’s G-tube. He calls it his tubie.”

“It helps him get more nutrition than he is able to eat, so he can grow and be strong.”

“When Rob was a baby, he was very sick. He was so sick he could not even learn to drink or eat, so he got the G-tube.”

“Now Rob enjoys eating and drinking and doing everything else kids like to do.”

As people *eat* with their mouths, we make a point *not* to refer to the supplements as “eating” or “putting food in”. We call it “doing his tubie” and “giving him extra nutrition”. Like all parents, we hope he will continue to be happy and continue to be proud of his body.

Thanks for being part of Rob’s “Village” and for the respect with which you treat this information.

Most sincerely,

Alice and Joe

Dear friends,

Now that it is summertime, when you see me without my shirt on you may be curious about how I look. You may also be curious about my extra drink or my syringe and G-tube.

If you say, “What’s that, Rob?”

I will say, “It’s my G-tube. In my family we call it my tubie.”

Then, if you say, “What is a G-tube.”

I will say, “A G-tube is a special tube the doctors and nurses put into someone’s stomach, with an operation, so they can get extra nutrition if they can’t eat and drink enough to grow and be strong.”

Then, if you say, “Why do you have a G-tube, Rob.”

I will say, “Because when I was a baby I was very sick. I had lots of operations on my heart, and I was so sick I couldn’t even learn to eat or drink. I have been working very hard with my parents and some special teachers and now I can eat and drink many things. I am very proud of myself. But it is still hard for me to eat and drink all that my body needs.”

Then, if you say, “What are those lines, Rob?”

I will say, “The lines are scars from the operations on my heart.”

Then, if you say, “Rob, you have been really brave!”

I will say, “You’re right!”

I don’t want to talk about this any more, now. Let’s play!

Your friend,
Rob



At Home...

I remember the day the representative from the home care company delivered our overnight feeding equipment. She arrived with an IV pole, pump and bags with lots of tubing. My baby's little nursery had been painted lilac and the crib sheeting was yellow gingham. The imposing hospital-like equipment was a glaring reminder of the medical side of our lives...but it wasn't how I wanted to see things on a daily basis. At first, I tried to soften it by wrapping colorful ribbons around the IV pole. A year later, I got rid of the IV pole completely. Instead, I bought a single decorative shelf that attaches to the wall. I put several teddy bears on the shelf,

along with the pump. I secured the pump to the shelf by attaching it to a dowel that was screwed into the shelf. I then placed a single hook higher on the wall. At nighttime, I hang the bag from the hook.

I have to say how unprepared for any of this my husband and I felt. The hospital really didn't help much in this regard. Our daughter had her tube put in at six weeks – no other option, due to her condition of congenital diaphragmatic hernia. We really thought it was a temporary thing, and the hardest part for me was accepting it as *not* temporary. This was much, much harder for me than my husband. The hospital sent us home on gravity feeds every

three hours – around the clock – without any help. We never qualified for nursing. I would nurse her twenty minutes each side as the hospital told me to do (this to a girl with one lung!). Then I would gravity feed her one ounce that took 30 - 40 minutes after which she would gag and retch. (She had a nissen fundoplication placed at six weeks also). Finally I would try to get us both back to sleep just in time to do it all over again.

Once, a neighbor came over to visit just as I was putting our two-year-old down for a nap. I was giving her a tube feeding in her bed. My neighbor said to my daughter, “Oh, are you eating your lunch?” I

Supplies...

Children who need nutritional care may be started on tube feeds in the hospital or at home. Referral to the home care company may come from the child's hospital or insurance case manager, physician, nurse, dietitian or from the family themselves. The home care company then checks the patient for safety and payment issues.

Products and services provided often depend on the type of company servicing the patient. Families may get their supplies for tube feeding from a local drug store; however, most families get them from a Durable Medical Equipment company (DME) or home infusion therapy company.

Both types of companies can provide the formula, pumps, bags, syringes, feeding tubes and supplies needed to care for the tube site or stoma. Some companies can also provide supplies for other needs such as intravenous or respiratory. Home care companies also offer additional services such as nursing and dietitians. The nurses can provide teaching and home visits

to patients who need this care. Dietitians can follow weight gain and tolerance to the formula and can suggest changes to the feeding.

Insurance Company Coverage determines how much the home care company will be paid. Most *indemnity* plans pay a 'Usual and Customary' fee or will negotiate individual payment with the company at the time of referral.

Managed care insurers negotiate a daily rate with the vendor for a specific length of time or authorization period, as determined by the case manager. Authorization depends on the child's diagnosis, anticipated progress or testing, and the individual case manager.

Medicaid, Mass Health and Commission for the Blind require a 6-month prior-authorization (PA) from Medicaid to the vendor. Some vendors will not provide any supplies until the PA is received which can take a number of weeks. Medicaid pays the vendor for 30 days of

supplies at a time, which means the company can ship only 30 days at one time.

If the patient meets the guidelines, *Medicare* also pays for 30 days of supplies at one time. Medicare has guidelines on the exact types of supplies that they will cover and the amount to be paid to the vendor.

The tube-feeding supplies can be delivered directly to your home. For travel away from home, most home care companies are able to deliver short-term quantities of tube feeding supplies to an out-of-town address.

In conclusion, tube feeding in the home has become more common over the years. Each home care company is different in terms of the products provided and the services available. Patients and their families should work with their physicians and case managers to select a company that best meets their needs.

Deborah Pfister, M.S., R.D., C.N.S.D.
New England Home Therapies

jumped in and said, "She already ate her lunch, and now she is having a tube feeding." We have tried to distinguish between oral eating and tube feedings.

We saved empty formula boxes, taped up the ends, and used the 100's of boxes for building blocks! We made some great structures and saved money by not buying large cardboard blocks!



Train built from empty formula boxes.

At School...

As our child has cardiac problems, the School Nurse suggested we make an emergency packet of information that would be useful to the EMTs if an ambulance becomes necessary. Written in a simple and easy to read format, this will be kept sealed, in a large envelope, separate from the general health records, so it can be easily and quickly retrieved. We included information about underlying medical problems, baseline vital signs, preferred hospital, hospital I.D. number, hospital specialists' names and phone numbers, etc. as well as information about the G-tube. A copy is also readily available at home.

It's great to connect my child's teachers, specialists and aides with the feeding therapist that we use. They can learn so much from the therapist, in a way that I am simply not equipped to teach them. I love to have the feeding therapist visit the classroom. That way she can observe, understand the routine, suggest feasible activities and therapies and, truly, become part of the special education team.

Most people have a hard time imagining why in the world a child doesn't eat. How many times have people glibly said, "Oh, I wish I had that

problem!"" (NO, you don't.) Each year at the start of school it's a draining, time-consuming process to explain to the teachers, aides and staff about why my child doesn't eat much by mouth. I explain that it's a combination of two powerful deficiencies: oral-sensory and oral-motor. Regarding oral-sensory issues, my child just doesn't welcome tastes and textures into her mouth the way a typical person does. The sensations that food in the mouth produce for her are extremely challenging and frightening. From an oral-motor perspective, she lacks so many of the skills to readily, safely handle food that goes into her mouth. I see her eyes widen, her tongue withdraw to the way back of her mouth, the drool start to pool then to spill. She is agonized about what to do with this item in her mouth. Her reaction is to withdraw from it, to gag, to vomit...anything but manipulate, chew and swallow it. After going through all of that by means of explanation, the average person usually asks, "Have you tried chocolate ice cream? Every kid likes chocolate ice cream." I take a deep breath, swallow my own frustration and despair, and go on to explain that taste has nothing to do with it - and I start all over again explaining the oral-sensory and oral-motor issues. Eating is so innate for most people

that it's almost impossible for them to grasp that taste isn't the major factor.

Each year, at the start of school, I present a document that summarizes my child's feeding background to the team of teachers involved with my child. This helps orient the team to my child's current feeding status. It is especially helpful for those teachers that have no experience with children with feeding difficulties. The document follows the following outline:

- Brief Medical History
- Eating History
- Oral Feeding Therapy Experience
- Current Oral Feeding Status
- Safety Issues
- Overall Oral Feeding Goal
- A Typical Day of Feeding at Home
- Current Comfortable Foods
- Oral Feeding Needs in the School Day
- Eating Independently – Games, Gimmicks and Strategies
- Reading the Signs
- My Availability and Other Resources
- Emergency Procedures

On the one day that I wasn't reachable by phone, my child's tube was accidentally pulled out by a classmate! Fortunately, we had left a spare G-tube with the school nurse. She was able to replace it without too much trauma.



Oral Feeding...

The therapeutic needs of our tube-fed daughter are specific not only to her lack of oral motor skills, but also to her low trunk tone and her reflux. We do a physical warm-up program before beginning her oral routine. As an infant, the physical warm-up was massage. As a toddler, it is an obstacle course that we set up with the help of an occupational therapist. The course challenges her balance, which increases trunk strength. We then follow a highly structured program to prepare her mouth. We use a variety of tools and vibration. We use the following in order: surgical scrub brush, wash cloth, NUK brushes (large hand-held type and rubber finger brush), and vibration. Although we end up in the high chair, it is the

shortest part of the routine (10 minutes max). We keep it upbeat and offer one food type at a time. We give her control and a place to put foods once "all done". We used sign language "more" and "all done" to give her control when she was not yet verbal. We always tell her what is being offered and encourage touching first (then adding in smell, kiss, lick, bite, chew – in that order) as she progresses. At first, it was very slow and discouraging (food was not touched at all, or simply dropped into the all done spot), but over time she slowly progressed. The key for us was to do this program (warm-up and food choices) every day, twice a day in a positive, upbeat way.

I think the people closest to us understand the lack of eating. But, it

is hard for others to fathom. I'm not sure it's that easy to explain either. We just keep the faith that she will eat someday. I'm very curious in ten or twenty years to see what she's like – her eating habits – her size – her outlook on food. Our joke is that she will grow up to become a famous chef or food critic.

We read many, many books to our son as he sat with his food, eating small amounts. It helped "distract" him, and it also made it easier for the grown-ups to stay at the table for a long time. As he has become older, sometimes we play a board game while he eats bites of food. It is a challenge to balance the opportunity for any food experience with developing good "meal-time habits".

Feeding Strategies...

There are a number of factors that must be considered when one develops a feeding plan for a child with an enteral feeding tube. First and foremost, it must be determined whether the child can safely receive any nutrition by mouth and if so, in what form. For example, a child may be able to safely take in soft solids, but aspirate thin liquids. A second factor to consider is the presence and/or degree of gastroesophageal reflux affecting the child. If the child's reflux is severe the type of feeding and method of delivery may be impacted by this. Finally, and very importantly, the child and family's lifestyle must be factored in to the feeding equation. The following information is meant to give you some basic definitions and ways to think of how to feed your "kid with a tube".

It is important to understand the meaning of terms used when discussing approaches to tube feeding. The following are terms you will hear used frequently:

- Continuous feeding: a tube feeding that is given at a slow rate over many hours (i.e. 30cc per hour over 10 hours)

- Bolus feeding: a tube feeding given over a short period of time (i.e. 5 ounces over 20 minutes)

In children who are able to take some nutrition by mouth, there are several options for feeding. These include oral feeding throughout the day, supplemented by an overnight continuous tube feeding. Another strategy is to offer oral feeding throughout the day, followed by small bolus feedings after each meal. A combination of these approaches can be used as well.

In children who are unable to take any nutrition by mouth often the easiest approach is to administer several bolus tube feedings throughout the day, often at mealtimes and bedtime. These children may also benefit from overnight continuous feedings.

For children in whom gastroesophageal reflux is a problem, feedings may be best tolerated when given in small, frequent boluses or as a continuous feeding.

Methods of administration of these feedings vary. Generally, a continuous feeding is given with a feeding pump. A feed-

ing pump runs off of a wall electrical socket or a rechargeable battery. Some pumps are attached to an IV pole and are left stationary; others are "portable" and can travel with the child. Most portable pumps fit into a backpack and can then be carried by the parent, the child, or hung on a stroller or wheelchair. Pumps are set to deliver the feeding at a specific hourly rate and most can be programmed to run for a set length of time (i.e. 20cc per hour for 12 hours).

On the other hand, bolus feedings can be given with a pump, by gravity using a feeding bag or syringe, or gently pushed in with a syringe. Generally, bolus feedings are given over a 20 minute period.

There are many ways you can feed your child who needs nutritional support via feeding tube. As your child grows the feeding strategy may change. It is very important to discuss feeding options with your child's doctor, nurse, or dietician. Together you can decide the right way to feed your child with consideration to your child's special needs.

Lori Parker-Hartigan, R.N.
Children's Hospital, Boston, MA

Reflux...

I can name every store and mall and every place we've ever been when our daughter has gagged and retched, and people have either rushed over to offer help or just stared or looked the other way. It's a way of life for us, and she hasn't yet outgrown it.

One of the most difficult parts of our daily lives has been dealing with reflux. As an infant, there was a lot of vomiting. Our daughter had difficulty keeping down a bolus greater than two ounces. As soon as I would complete a slow gravity-fed bolus, she would projectile it across the room. It was sad. It was frustrating. It was messy. The vomiting occurred between 3 - 8 times each day. It improved over time, especially as we adjusted when/how/where we tube-fed her. We raised the head of her crib. We placed her in a car seat or bouncy seat after feeding. And we adjusted the volume of each bolus. I also became better at coping with vomit. I always carried a change of clothing for her, and for myself.

As she got bigger, and more upright, the vomiting subsided. At three years, she now vomits 1-2 times a week. And, we have taught her coping skills, such as getting to the bathroom and vomiting into the toilet. This gives her a level of control as well. The reflux continues and definitely interferes with her comfort in oral eating.

Morning coughing and mucus were reduced when I removed old pillows from his bed and replaced them with new hypoallergenic dust-mite proof pillows.

When my son is sick and not tolerating formula, I mix Pedialyte

with frozen 100% white grape juice. This lets me give calories along with a balanced electrolyte diet.

Figuring out the right rate for our daughter was a process. At first we started with a low speed as recommended by our doctor. Every two weeks we added 5cc/hr until our daughter started having trouble keeping her food down in the morning. We would try to keep her calm in the morning -- no food and low activity for at least 1-2 hours after we turned off the pump. Also we would start the pump at least 1.5 - 2 hours after she ate so her stomach wouldn't be full at the start of her tube feeding. If we had trouble

keeping down a new formula blend we subtracted 5cc/hr each night until we were keeping food down and would start the process over.

Mornings have always been our worst time for food. I find that having him drink or giving some water by tube, and then waiting a bit of time before giving food or formula helps. I don't know whether the water "stretches" the stomach, or helps any overnight mucus go down, or just "primes" the GI tract, but it does help him to tolerate food in the morning.

The Benefits of a Case Manager...

Having a child with a G-tube changes many things in your life. Accessing your insurance benefits for supplies, equipment and other resources presents a surmountable challenge but can be fraught with roadblocks. Most insurance companies have a Case Management Department. A case manager can serve as a liaison to the equipment company, can help coordinate services, and advocate for you and with you in dealing with other health care providers. The case manager can also be a source of support and education.

Case managers are a resource for other programs or support groups that are available in the community. For those of you who are already involved with Kids with Tubes, you are a step ahead having made an important connection with others sharing many of the same issues.

In most circumstances, when your child's needs are uncomplicated, a case manager may be a short-term contact to help you get connected with

a health care provider. In more complex situations, a case manager may assist a family in maximally using their insurance benefits and helping them to access alternate funding. Most insurance benefits have either a cap or a maximum benefit for durable medical equipment and understanding how to get the most out of your policy as well as the other resources available to supplement that, is all part of how a case manager can help you.

Case managers are usually registered nurses but may be from other disciplines. You should expect him/her to have experience/expertise in pediatrics and issues associated with kids with tubes. A case manager should be a supportive ally who helps you in the overall management of your child's needs, supporting as needed, guiding as appropriate and empowering you to be the best manager and advocate for your child.

Donna Fruman, R.N., Case Manager
Blue Cross Blue Shield



Our Next Newsletter

Therapies for the Tube-fed Child

The Spring 2001 issue of *Kids with Tubes News* will address various therapies available for kids with tubes. We would love to include your stories on this topic. If you would like to contribute a story to the newsletter, please send your article to info@kidswithtubes.org or Jill Crisman at 22 Woodpark Circle, Lexington, MA 02421. The deadline for submissions is February 1, 2001. Write your story now so that you don't forget!

Thank You

Kids with Tubes is supported by donations from institutions and families and friends of tube-fed children. Donations of all sizes are welcomed and appreciated.

This issue of *Kids with Tubes News* has been produced with funding from New England Home Therapies, MeadJohnson Nutritionals, and a financial award from The Haussein Early Intervention Parent Leadership Awards. Kids with Tubes is grateful to these organizations for their generous support.



Recent Quarterly Seminar Summaries

Sensory Integration

On May 6, 2000, Trisha Dolan addressed our group on the topic of Sensory Integration and the Tube-fed Child. Approximately 25 people attended. Ms Dolan provided each participant with a folder of handouts on Sensory Integration, covering evaluation and intervention, types of sensory defensiveness, school checklists, and tactile activities. Her talk described sensory integration, defined the sensory systems, and explained the functions of sensory registration, modulation and discrimination. She also reviewed the evaluation process and potential interventions.

First Annual Kids with Tubes Picnic

Our first picnic was held at the Beaver Brook Reservation in Waltham, MA on July 22, 2000. Due to the strong threat of rain on the scheduled date, we had to postpone the picnic for a week. Unfortunately, that limited the number of families that could participate. But the seven families that were able to attend enjoyed the good company, ball playing, and playground. We plan to make this an annual tradition.



Twins Lindsey and Jillian Shapiro at the Kids with Tubes Picnic

Upcoming Quarterly Seminars

January 13, 2001

Tube Tips

April 7, 2001

Transitioning to Oral Feeding

July 14, 2001

Picnic

October 13, 2001

Therapies for the Tube-fed Child

Save the dates! We plan to continue with our Quarterly Seminar series in the year 2001. So, save the dates on your calendars, and stay tuned for more information on the topics.

Dates and topics are subject to change. Refer to the Quarterly Seminar announcements for exact time and place. Pre-registration is necessary by calling (781) 275-0469.

Regional Support Groups

Kids with Tubes facilitates informal regional support groups. The groups are organized by parent coordinators throughout New England. As of this fall, many of the groups will be posting their meetings in this newsletter. These meetings provide opportunities for discussing individual experiences, tips, and concerns. Parents are invited to attend any meeting that is convenient for them. You should contact the coordinator of the meeting in advance so that she can notify you of any last minute changes.

Boston, Massachusetts Area:

If you would like to meet in this area, please call Sheryl Soukup (617) 364-6769, and she can tell you when the next meeting will be.

Brockton/Stoughton, Massachusetts Area:

- Sunday Nov. 19 at 2:00 PM at the Good Samaritan Hospital Ground Floor Community Room (off Rt. 24 on the Brockton-Stoughton line)

Please call either Cathy Atkins (508) 946-1147 or Brigitta Brodax at (508) 238-6966 to RSVP. Additional meetings will be planned for this winter so call for more information on places and times.

Burlington, Massachusetts Area:

- 2nd Tuesday of every month at the Food Court in the Burlington Mall for coffee at 9:30 AM
- Please call Jill Crisman at (781) 402-0216.

Newton, Wellesley, Framingham Massachusetts Area:

- Monday Nov. 13, 7:30 PM at the Cheesecake Factory on Rt. 9 in Chestnut Hill
- Thursday, Jan. 11, 7:30 PM at the Ming Garden, Rt. 9 in Chestnut Hill
- Tuesday, March 20, 7:30 PM at the Olive Garden in Framingham Shopper's World

Please call Marlene Shapiro at (508) 788-0632.

Stoneham/Somerville, Massachusetts Area:

- 1st Tuesday of every month at 7:00 PM at a group member's home

Please call Beth Corvi (781) 438-5249 to RSVP and get directions to that month's meeting location.

Tewksbury, Massachusetts Area:

- This group meets about every three months at the Appleby's in Tewksbury.

If you are interested in meeting with the group there please email (preferred) to Joanna Magazzu (jmagazzu@genetics.com) or call her at (978) 664-2760.

Western Massachusetts Area:

If you would like to meet in this area, please call Kathy Smiarowski (413) 247-9980, and she can tell you when the next meeting will be.

Upper Valley (New Hampshire and Vermont) Area:

If you would like to meet in this area, please call Helen Norton (802) 785-4615, and she can tell you when the next meeting will be.

Connecticut:

- 3rd Thursday of every month at 7:00 PM, beginning on November 16 at Border's Books in Farmington CT, near the West Farms Mall

Please call Karen O'Hanlon at (860) 693-1616.

Kids with Tubes

support for parents and caregivers of tube-fed children

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Irene Walborsky
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The information contained in *Kids with Tubes News* has been carefully compiled from sources believed to be reliable, but its accuracy is not guaranteed. The information is given with the understanding that Kids with Tubes is not engaged in rendering medical, therapeutic, nutritional or other professional advice. If such advice is required, the reader should seek the services of a competent professional. Any opinions expressed herein by the contributors are their own and not necessarily those of Kids with Tubes.

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children

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WE'RE ON THE WEB!
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