Feeding Tubes, Travel, and Disney

Marie B. Latta, M.Ed.

Have you wondered where you could go with your feeding tube and other equipment to have a relaxing vacation? After years of not traveling, I tried Disney World in Orlando, Florida, and the Disney Magic cruise ship, and found that place. I am not peddling Disney, but I want to share why my experiences were so—as Disney says—“magical.”

Disney welcomes guests with specific needs. So if you, like me, have been saying traveling presents too much to deal with or you dread the airline experience, it may be time to rethink. Disney has built accessibility into their daily operations. Their accessible ground transportation is the biggie for me. But beyond that, they are prepared for people with all sorts of conditions and want you to participate but never feel patronized.

Planning

I hadn’t flown for about ten years when, in 2008, my daughter-in-law convinced me to go on a Christmas cruise with them. I flew to Orlando alone and met my family at the Disney terminal in the airport, where we were transported by bus to the Disney Magic cruise ship at Port Canaveral. In 2009, I met my family again. We spent five days in Disney World, then boarded the Disney Magic for a seven-day cruise.

Years earlier I’d decided I wouldn’t fly because I didn’t want to risk my wheelchair being damaged. When I added my feeding tube, tracheostomy, and ventilator, the anticipated challenges multiplied. While any trip takes preparation, for those of us with a variety of conditions, preparation reaches a new level. Here’s what I learned about planning.

• Start as early as possible and have your own travel agent. Ideally, you can find an independent travel agent.

Disney, cont. pg. 10

Pain in the Gut

Klaus Bielefeldt, MD, PhD

Intestinal failure, while rare, constitutes a severe chronic problem that often requires complex medical interventions—from insertion of feeding or decompression tubes to initiation of parenteral nutrition, or even intestinal transplantation. These therapies can sustain life. However, once on these therapies many patients continue to have symptoms and problems with nausea, bloating, discomfort, and pain. My goal is to discuss our current understanding of visceral pain (pain that originates in the inner organs, like the stomach) and visceral pain management.

Acute vs. Chronic Pain

We all have experienced pain and know that it is more
it is typically triggered by a potential injury (e.g., heat) and quick action is required to prevent harm.

The perception of threat or danger exists when pain originates in the inner organs as well. Further, this visceral pain is often accompanied by other sensations, such as shortness of breath or nausea. Thus, it may not be surprising that it is typically judged as more unpleasant than similar pain from other sites of the body and that it is also associated with a stronger emotional reaction. Moreover, you may be able to move your hand away from heat, but you certainly cannot move your stomach away from anything when it hurts from inside. Thus, visceral pain has unique aspects that overall make it more difficult to deal with.

Things get even more complicated when pain becomes chronic. Chronic pain is often as alarming as acute pain. Thus, physicians and patients deal with it as they do acute pain and ask for tests to address the fear that there may be some new or different problem. But chronic pain has often lost its “physiologic relevance” as a red flag, as a warning about impending danger. More often than not, there is no truly alarming or acute problem that can or needs to be fixed. Under such circumstances, chronic pain has become its own problem.

Sensory Mechanisms within the GI Tract

We typically think about pain as a complex experience triggered by some potentially harmful stimulus. This concept requires a sensor to register the stimulus and send the information to higher centers in the nervous system. In our skin, we have many specialized sensors. These inform us about a light touch, a sharp prick, and contact with a cold or hot object. With increasing stimulus intensity, we start feeling pain. Does this also apply for the gut?

Detailed physiologic experiments tell us that much sensing is going on in the gastrointestinal (GI) tract. Sensors register the temperature, flow or chemical composition of intestinal contents, and filling of hollow viscer.a. However, most of this information never reaches our consciousness. We can feel some signals, such as those related to filling (distension), tone or contractions of GI muscles, or some chemicals, most notably acid. The more intense the stimulus, the more it is felt; eventually it may exceed the threshold for discomfort and is perceived as pain.

Over the last few decades, we have learned about specific pathways that are important for the normal function of these sensors and that may play a role in the steps that ultimately lead to pain. The following example may show the importance of this research: More than ten years ago, researchers at Johns Hopkins University identified a protein that is present in the membrane of specialized nerve cells and that may contribute to pain sensation. This protein forms a channel (a type of pore) that can open and allow the flow of ions across the cell membrane of these nerves. The regulated flow of such ions constitutes a signal that can then be sent “upward” and may ultimately reach the brain. What is unique about this ion channel is that it can be activated by extracts of hot and spicy peppers.

If you have eaten a habanero pepper, you know it truly burns. If you go a step further and inject the extract of this pepper under the skin, you would experience a severe burning pain. This ion channel, later named TRPV1, appears to be a good candidate for a pain sensor. Indeed, animals lacking this receptor show different pain behavior in specially designed experiments. In humans, we find increased nerve endings with this ion channel in the GI tract of patients with problems such as acid reflux, inflammatory bowel disease, or diverticulitis, all conditions associated with pain.

Several other molecules that send painful signals to the central nervous system have subsequently been identified. These may also play a role in the initial steps of pain sensation. Why is this important? Because if we learn about some of the mechanisms involved in pain signaling, we can work on treatments that target these molecules. In the case of TRPV1, blockers have been developed and are currently in early phases of clinical testing.

Illness May Increase Pain Sensation

Let’s go back to the observation that the more intense a stimulus, the more severe the pain it may cause. This relationship between stimulus strength and perceived pain is not static. For example, illnesses “sensitize” the system, transforming a moderate touch into a painful experience. Most clinicians refer to such states as hyperalgesia, a term you may have heard. We have learned how our sensory system may be up-regulated during illnesses and how this can contribute to pain.

Take inflammation as an example. During colitis flares, many different mediators are produced and released. These substances include...
Pediatric Intestinal Meeting

Specialists gathered in Chicago in September for the Sixth International Pediatric Intestinal Failure and Rehabilitation Symposium, sponsored by Children’s Hospital of Pittsburgh at UPMC and Children’s Memorial Hospital, Chicago. The Oley Foundation was fortunate to be there as an exhibitor and to have a staff member attend the sessions, which were very informative.

On the first day of the symposium, “Family/Professional Day,” four patient stories were presented (by the patient or a caregiver), followed by presentations and breakout sessions directed at families and caregivers. Topics revolved around intestinal adaptation and transplantation, and included: developmental issues in children with chronic illness and/or intestinal transplantation, transitioning to adult care, pediatric feeding disorders, and medication compliance issues.

On Friday (devoted to “Intestinal Rehabilitation”), Florence Lacaille, MD, from Hôpital Necker-Enfants Malades, Paris, France, delivered the keynote address, “Intestinal Failure Management and Prevention of Cholestasis.” Other highlights of Friday’s program included presentations on butyrate, GLP-2 and growth hormone; the dysmotile bowel; bacterial overgrowth; catheter-related infections; and a panel discussion on the optimal timing for referral to an intestinal rehabilitation and transplantation center.

Saturday was devoted to transplantation. Among other topics, experts discussed the latest outcome data from two databases (the International Transplant Registry [ITR] and the Scientific Registry of Transplant Recipients [SRTR]); how to reduce mortality on the intestinal transplant waitlist; and “tissue engineering of small intestine” (still many years in the future for humans).

A mother of a child on home parenteral nutrition who was able to stay for most of the conference said, “[After the conference.] I met with our doctor and went over everything from the conference (he was there too) and he was very receptive. It was...one of the best inclusive care conferences we’ve had...praise God! And much of it was from attending the conference. I came away from the conference with a much clearer understanding of my daughter’s short bowel issues and hope for improving her care and quality of life.”

We are hoping some of the conference participants will be writing soon for the Oley newsletter. Keep your eyes open! Watch, too, for information about the next International Pediatric IF and Rehabilitation Symposium, which will be held in 2012.

Help Oley Reach Others

The Oley Foundation relies heavily on volunteers to staff exhibit booths at professional and consumer conferences throughout the country. We could use your help! As a volunteer, you would hand out information and answer questions—about Oley, but also often about your own experiences. You would also have an opportunity to visit other exhibits and talk to clinicians.

After staffing the Oley booth at a professional conference in Houston, Amelia recently wrote, “I was able to share my story of coming home with my PEG four years ago...and how much Oley’s info helped me....It seemed like an ‘Ah ha!’ moment to several people—to have people that deal with this every day [available through Oley] to not necessarily give advice, but just be able to share their experience and what has worked for them.

“I always assumed Oley was very well known, but some of the people visiting the table had never heard of Oley, despite sharing with me that they discharge multiple patients a week with a new PEG/G/J/ PICC, etc. So there is a message to be shared and we, the ones living with HPEN, are in a place to do that! I, of course, had my backpack with my pump and food, and it was almost startling for some of these professionals to realize you can lead a pretty normal life on HEN.... It was a great success. Thanks for the chance to help out Oley!”

Upcoming Exhibits

We have reserved exhibit space at the following conferences in November and add new ones to our list weekly. For exhibit times and other details, contact Katie Swensen at kswensen18@gmail.com or call the Oley office at (800) 776-OLEY.

- Nov. 11: Ohio Chapter of A.S.P.E.N., Youngstown, OH
- Nov. 19–21: Infusion Nurses Society, Washington, DC
Tube Talk

Feeding through an Ostomy Bag Using a Universal Catheter Access Port

Some time ago we published a tip on how to adapt an ostomy bag to allow a feeding tube to pass through it without leakage (Lifeline Letter, July/Aug 2002). We recently shared that tip with Oley member Emily Convery, who adapted the suggested procedure a little and sent us wonderful photos, along with some updated information. The article below reflects much of the original, with Emily’s photos and updates. Find larger versions of the photographs, as well as additional images, at www.oley.org

Please discuss this idea with your physician before you try it.

Most physicians see important advantages to a patient using his or her gastrointestinal tract, even if accessing it is somewhat complicated. For example, tube feeding is sometimes done through a small bowel ostomy that is the site of some secretions and requires an ostomy bag. This might happen if the patient has a loop small bowel ostomy and feeding into the more distal segment of the bowel is desirable, or if the patient has a Roux-en-Y feeding jejunostomy.

The ostomy bag is essential so the secretions from the proximal bowel do not irritate the skin, so the challenge is to insert the feeding tube through the ostomy bag and into the distal segment for feeding. This can be achieved by gluing a universal catheter access port (a soft plastic cone) into the ostomy bag. The directions below take you through this process with some helpful hints by Emily.

Emily uses a two-piece ostomy system: “The barrier (also known as a wafer or base plate) stays on my skin around the stoma and the bags fit onto it. This is crucial for protecting the skin around my stoma because the base only gets changed every three to five days.” The adapted bags, she says, “have worked wonderfully! I am now able to go to school and work and function just fine with the tube hooked up and hardly anyone notices.” When she doesn’t need to use a feeding tube, Emily applies a regular bag or a stoma cap to the barrier.

Photos 1–3: Preparing the Wood Blocks

Photos 5–7: Gluing the Port into the Ostomy Bag

Photos 8–10: Gluing the Insert into the Bag

Gluing the port into the ostomy bag:

1. Put the outer ring on the port (soft white cone) and place them tip down into the hole in the wooden block (photo 5).
2. Put glue around the perimeter of the outer ring (photo 6).
3. Place the ostomy bag face (hole-side) up on top of the port on the block, centering the bag’s hole over the port (photo 7). Emily notes, “This makes the pointed part of the tube adapter face outward; I had tried having the adapter point inward, but my stoma was getting a little sore and actually bleeding a little bit if I had it going this way.”
4. Place the inside ring on the hard blue cone (photo 8), and carefully apply a small amount of glue to the exposed surface of the inside ring (photo 9).
5. Poke the blue cone (tip side down) through the opening on the ostomy bag, through the back of the ostomy bag, and into the white cone (photo 10). This will create a hole in the ostomy bag, and leave the port sandwiched between the inner and outer rings.
6. Hold in place until the glue sets (about 1 to 2 minutes). Remove the blue cone.
7. Snip the tip of the port carefully, making a hole just large enough to fit the feeding tube through. Emily notes, “The tip of the blue cone

Equipment needed:

• universal catheter access port (a “Christmas tree,” Hollister item #9779). Kit includes:
  - the port itself (a soft white cone)
  - hard plastic blue cone (for inserting the port)
  - plastic rings (inner and outer, to help hold the port in place)
• block of wood, approximately 2” x 4” x 4”, with a hole the diameter of the port’s outer ring drilled through it. (Emily notes, “I was able to go to Home Depot and get a couple of blocks of wood for about $1 each; the hole was easily made using a 1” drill bit I got for about $5 and which fit into a standard drill. It was very easy.” See photos 1–3.)
• disposable gloves (to protect your fingers from getting glued together)
• fast-acting adhesive, such as SuperGlue
• ostomy bag (Emily notes: “I use urostomy pouches with the tube. I use three different sizes, depending on how much drainage I am having and what clothing I am wearing. The small one is a micro-pouch, the medium one is a pediatric urostomy bag, and the biggest one is an adult urostomy appliance. [See photo 4.] The barrier I use fits all three sizes, as well as the stoma cap or small bag I wear when I do not have the tube in.”)

Some time ago we published a tip on how to adapt an ostomy bag to allow a feeding tube to pass through it without leakage (Lifeline Letter, July/Aug 2002). We recently shared that tip with Oley member Emily Convery, who adapted the suggested procedure a little and sent us wonderful photos, along with some updated information. The article below reflects much of the original, with Emily’s photos and updates. Find larger versions of the photographs, as well as additional images, at www.oley.org

Please discuss this idea with your physician before you try it.

Most physicians see important advantages to a patient using his or her gastrointestinal tract, even if accessing it is somewhat complicated. For example, tube feeding is sometimes done through a small bowel ostomy that is the site of some secretions and requires an ostomy bag. This might happen if the patient has a loop small bowel ostomy and feeding into the more distal segment of the bowel is desirable, or if the patient has a Roux-en-Y feeding jejunostomy.

The ostomy bag is essential so the secretions from the proximal bowel do not irritate the skin, so the challenge is to insert the feeding tube through the ostomy bag and into the distal segment for feeding. This can be achieved by gluing a universal catheter access port (a soft plastic cone) into the ostomy bag. The directions below take you through this process with some helpful hints by Emily.

Emily uses a two-piece ostomy system: “The barrier (also know as a wafer or base plate) stays on my skin around the stoma and the bags fit onto it. This is crucial for protecting the skin around my stoma because the base only gets changed every three to five days.” The adapted bags, she says, “have worked wonderfully! I am now able to go to school and work and function just fine with the tube hooked up and hardly anyone notices.” When she doesn’t need to use a feeding tube, Emily applies a regular bag or a stoma cap to the barrier.

Photos 1–3: Preparing the Wood Blocks

Photos 5–7: Gluing the Port into the Ostomy Bag

Photos 8–10: Gluing the Insert into the Bag

Gluing the port into the ostomy bag:

1. Put the outer ring on the port (soft white cone) and place them tip down into the hole in the wooden block (photo 5).
2. Put glue around the perimeter of the outer ring (photo 6).
3. Place the ostomy bag face (hole-side) up on top of the port on the block, centering the bag’s hole over the port (photo 7). Emily notes, “This makes the pointed part of the tube adapter face outward; I had tried having the adapter point inward, but my stoma was getting a little sore and actually bleeding a little bit if I had it going this way.”
4. Place the inside ring on the hard blue cone (photo 8), and carefully apply a small amount of glue to the exposed surface of the inside ring (photo 9).
5. Poke the blue cone (tip side down) through the opening on the ostomy bag, through the back of the ostomy bag, and into the white cone (photo 10). This will create a hole in the ostomy bag, and leave the port sandwiched between the inner and outer rings.
6. Hold in place until the glue sets (about 1 to 2 minutes). Remove the blue cone.
7. Snip the tip of the port carefully, making a hole just large enough to fit the feeding tube through. Emily notes, “The tip of the blue cone

Equipment needed:

• universal catheter access port (a “Christmas tree,” Hollister item #9779). Kit includes:
  - the port itself (a soft white cone)
  - hard plastic blue cone (for inserting the port)
  - plastic rings (inner and outer, to help hold the port in place)
• block of wood, approximately 2” x 4” x 4”, with a hole the diameter of the port’s outer ring drilled through it. (Emily notes, “I was able to go to Home Depot and get a couple of blocks of wood for about $1 each; the hole was easily made using a 1” drill bit I got for about $5 and which fit into a standard drill. It was very easy.” See photos 1–3.)
• disposable gloves (to protect your fingers from getting glued together)
• fast-acting adhesive, such as SuperGlue
• ostomy bag (Emily notes: “I use urostomy pouches with the tube. I use three different sizes, depending on how much drainage I am having and what clothing I am wearing. The small one is a micro-pouch, the medium one is a pediatric urostomy bag, and the biggest one is an adult urostomy appliance. [See photo 4.] The barrier I use fits all three sizes, as well as the stoma cap or small bag I wear when I do not have the tube in.”)
will make a hole in the bag large enough for the tube to fit through. I prefer not to completely cut the remaining bag out from the center of the hole because it prevents secretions/drainage from accumulating in the cone.”

8. After experimenting with the adapted bags, Emily added a step to glue the tube in place in the port. But note: you need to measure the length of the tube before you glue it. This way when you put the bag and tube in place, the tube will be situated appropriately in the distal bowel, as recommended by your physician. Emily says, “I put a thin layer of glue inside the cone after the tube has been put through to prevent the occasional leaking I had there, because the cone does not make a tight enough seal.”

9. To prepare for a feeding, insert the feeding tube that comes out of the port into the distal bowel and attach the ostomy bag to your body.

Emily prepares several bags of various sizes at once, so they are ready when she needs them (photo 4 with tubes, and photos 11–13, without tubes). Emily notes, “It is important to wait twelve to twenty-four hours before using the bags, to allow the glue time to dry—even if it is labeled ‘quick dry.’ I lay them all out on a trash bag or cheap plastic tablecloth while they dry in case any of the glue runs. (I had to cut one out of my carpet once.) I also recommend wearing gloves when dealing with the glue because it’s sometimes painful if you get it on your hands. Also, the bags can be used multiple times. I get special cleaners for ostomy appliances from my medical supply company to wash them when they are not in use.”

—Emily Convery
em42@me.com

An Alternative Using a Baby Bottle Nipple

Gail Waldby, MD, sent us a tip for adapting an ostomy bag using a baby bottle nipple, developed by Jarvis Haugeberg of Huron, SD. Step-by-step directions with photos for Jarvis’s design can be found online at http://generalsurgeonlinks.com/compressionfittingtubes.htm. Questions can be directed to Dr. Waldby at gwaldby@willinet.net. If you don’t have Internet access and would like a copy of the directions, please call Oley at (800) 776-OLEY.

Send your tips, questions, and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or e-mail metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

---

Medicare Competitive Bidding

Medicare has begun implementing phase one of its competitive bidding program. Under this program, Medicare solicited bids from home care providers in nine metropolitan areas for a select group of DME products. If you are a Medicare beneficiary and reside in one of the areas listed below, beginning in January 2011 you may see changes in where you can obtain certain durable medical equipment (DME) products, including enteral (EN) nutrition supplies.

The metropolitan areas included in this first phase are: Riverside/San Bernardino, CA; Miami/Ft. Lauderdale and Orlando, FL; Kansas City, MO; Cincinnati and Cleveland, OH; Charlotte, NC; Pittsburgh, PA; and Dallas/Ft. Worth/Arlington, TX.

Home care providers wishing to service Medicare beneficiaries in these areas submitted bids on a number of DME products selected by Medicare, including EN nutrients, equipment, and supplies; oxygen supplies and equipment; power wheelchairs, scooters, and related supplies; complex rehabilitative power wheelchairs; diabetes supplies; CPAP and related supplies; and hospital beds, walkers, and accessories.

As of October, Medicare was completing the process of awarding contracts to the “winning bidders.” There will be multiple “winners” for each product category in each metropolitan area.

During the last three months of 2010, Medicare is expected to notify affected beneficiaries to which home care providers are authorized to service them for each product group. If your current home care provider is not on the list, and you feel switching providers would be a hardship, talk to your current provider about whether an exception could possibly be made.

This program will impact you and you may be required to change home care providers if:
• You are on Medicare; and
• You live in one of the nine metropolitan areas listed; and
• You are using one or more of the product categories listed above.

If you are on Medicare and have to purchase EN supplies while visiting one of these select areas, you may have to purchase your supplies from one of the Medicare contract suppliers. We suggest you contact your home care provider to make arrangements in advance if you plan to travel to these areas.

For more information, go to http://dmecompetitivebid.com.

---

Equipment-Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation’s Equipment-Supply Exchange at www.oley.org! The list of items available is updated every Monday.

Questions? Contact Oley volunteers, Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351 between 9 a.m. and 4 p.m. EST.
Nutrition and You

Balance

“Balance”—we hear the term all the time. In the case of nutrition, it means “a state of equilibrium.” That is, if you “balance” what you take in nutritionally with what you put out in energy and activity, you will be “in balance.” It is not unusual for home parenteral and enteral nutrition (HPEN) consumers to watch intake and output (I and O) to reflect fluid balance, but it is also important to monitor I and O for nutritional balance. Weight loss or weight gain can result from too little or too much fluid intake from oral, enteral, and/or parenteral sources. However, it is important to remember that weight balance can also depend on calorie balance. Weight loss or gain due to changes in calorie I and O may be more gradual than weight changes due to fluids.

Measuring Needs

So how many calories do you need each day? There are a lot of ways to figure this out. There are Recommended Daily Allowances (RDAs). These group males and females in different categories and determine calories needed by age. There are also some general guidelines based on calories per kilogram. But to most accurately know how many calories you need, you need to know what your basal or resting metabolic rate (RMR) is and the average amount of activity you do each day. Combining those two factors will approximate your daily “energy expenditure” or calorie needs (calories [kcal]/day = RMR calories + calories for activity).

When you started on HPEN, your clinicians would have calculated your overall calorie and nutrient needs to provide the enteral or parenteral formula that would help you maintain optimal health. These numbers should be recalculated if your medical condition, weight, or activity level change significantly.

RMR is often estimated using equations. This estimated RMR varies among individuals, and according to the equation used. The activity factor, added to the RMR to determine daily calorie needs, is also estimated; your clinician may adjust the factor to better reflect your activity level. RMR in adults is often estimated using the Mifflin St. Jeor Equation. Let’s use this equation to estimate the RMR for a 45-year-old woman who weighs 130 lbs (59 kg) and is 5’4” (162.5 cm) tall. Then we’ll add an additional amount of calories to the RMR to account for activity (we will estimate she needs another 30% of her RMR for minimal activity).

**Equation (note that equation is adjusted for gender):**

Male: RMR (kcal/day) = \[(10 \times \text{wt in kg}) + \left(6.25 \times \text{ht in cm}\right) - \left(5 \times \text{age in yrs}\right)\] + 5
Female: RMR (kcal/day) = \[(10 \times \text{wt in kg}) + \left(6.25 \times \text{ht in cm}\right) - \left(5 \times \text{age in yrs}\right)\] - 161

- Convert pounds (lbs) to kilograms (kg) by dividing lbs by 2.2 (130 ÷ 2.2 = 59)
- Convert inches to centimeters (cm) by multiplying inches by 2.54 (162.5 x 2.54 = 162.5)

\[\text{RMR} = (10 \times 59) + (6.25 \times 162.5) - (5 \times 45) - 161 = 1220 \text{ kcal/day}\]

Calories for activity: 1220 x 30% = 366

**Daily calorie needs for this 45-year-old, minimally active woman: 1220 + 366 = 1586 kcal/day**

Your Balance, Your Weight

The “balance” comes in as you monitor your body weight.

- Are you gaining weight? If so, why? Could it be due to less exercise or activity (because you’ve been feeling bad, it’s too cold to go outside, or you’ve suffered an injury, for example)? Are you absorbing more oral calories?
- Are you losing weight? If so, why? Could it be due to more exercise or activity because you have been feeling better? Are you no longer able to eat orally? Could you be malabsorbing nutrients? Are you infusing your entire amount of feeding, whether EN or PN?

Whether you are a consumer of EN or PN or eat a regular diet, you have to balance the calories you take in with what you expend in activity and exercise. How is your balance? Need help? Contact your registered dietitian or send us a question!

*This column has been compiled and reviewed Carol Breton-Jones, PhD, RD; Laura Matarese, PhD, RD, LD, FADA, CNSD; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, PhD, RD, CNSC.*
Mailbox: Videos Very Helpful!

Thank you for offering video resources about pediatric tube-feeding (“Get Permission” and “Tube Feedings Are Mealtimes Too!”). My infant daughter had a Mic-Key button placed at four months to help her gain appropriate weight for heart surgery. Tube-feeding was essential for her survival. Now she is medically stable. We are working with therapists to encourage oral feeding. The videos illustrated much of what we do during therapy. I am the only family member present at her therapy sessions, so I relay our strategies to my husband, parents, and in-laws. They were able to watch the videos, which really helped them in their understanding of the process. We plan on borrowing more to watch!

—Beth Ballard

2010 Conference DVDs Now Available

Miss the conference or want to see a session again? DVDs of many 2010 Oley conference sessions are now available to borrow, free of charge, including:

- Main Session Day I: Featuring Sharon Rose, 42 years on HPN; intestinal failure management; preserving vascular access.
  Plus! Welcome/Awards Ceremony
- Main Session Day II: Featuring current thinking on micronutrients; improving your healthcare team relationship; HPN liver disease & lipids.
  Hot Topics in HPN Research: fish oil–based PN lipid emulsion; HPN quality of life; self care and blood drawing practices’ effect on CVAD longevity.
  Plus! In Loving Memory
- Tube Feeding Workshop: Featuring advice on leaks; enteral access for the complicated patient; food & drug interaction; and more!
  Plus! Breakout Session: Understanding Your Lab Values

For a complete list of DVDs/videos available from the Oley library, visit www.oley.org/video_dvd.html or call (800) 776-OLEY.

New PN Patient Assistance Program

Baxter Healthcare has launched a patient assistance program, myPN Support Program, aimed at supporting patients in need of parenteral nutrition (PN) while the patient tries to identify potential insurance alternatives. Baxter states, “The myPN Support Program provides temporary assistance for eligible...patients who are uninsured or underinsured….Patients who qualify will have [CLINIMIX] available to them even if they experience changes in their insurance status.” Program participants will also receive help to identify insurance opportunities and resources.

To be eligible for the program, you must not be covered by any private, public, or Medicare Part D prescription program, and your income must fit within the levels determined for the program (based upon Federal Poverty Level for the size of the household).

For more information on the program, call (888) 852-7948 or visit the Web site—“coming soon!”—at www.mypnsupport.com.
Scenes from the 2010 Oley Conference in Saratoga Springs
...join us next year in Minneapolis!
Coping Skills

Disney, from pg. 1

booking agent (not a Disney agent) who does not charge you but is paid by Disney for the business. Friends of my son and daughter-in-law are agents in Texas; they are exceptional problem solvers and we’ve done everything via phone and e-mail. (JoAn and Clif Hale, Cruise One, 817-448-9404, selah50@sbcglobal.net). I booked the Disney trips through them, but they do book other cruise lines and could help look for other accessible ones.

Disney-Specific Preparation

• Disney has a number of forms it requires everyone to fill out prior to a cruise. These include a medical form. They are available online (disneycruise.disney.go.com) and completing them makes boarding the cruise much smoother. Pay attention to the deadlines listed.

• You can purchase a transportation package ahead of time. This will free you of baggage. When you check your baggage at your home airport, it will be tagged for your Disney destination and will be handled through to your arrival. I checked my luggage in Atlanta and the next time I saw it was in my destination room. Oh, the freedom from having to manage luggage! (There is an additional fee for this service; I paid about $70 to have my luggage handled through to my destination.)

• Definitely purchase insurance for emergencies, such as medical evacuation. Without insurance, such an unexpected event would cost more than “an arm and a leg.”

• The “Special Services Information Form” is an optional form you can print out from the Disney Cruise Web site, then return by fax or mail. It has a place for your physician to report on any current medical condition(s) and medication. It also allows you to make arrangements for a wheelchair, oxygen, and special dietary needs. Again, pay attention to deadlines. This form must be received at least fourteen days prior to the cruise’s sail date.

Shipping Formula

• I shipped my feeding tube formula ahead. Disney has a warehouse in Canaveral, Florida, where I boarded the ship. I carefully marked my supplies (based on Disney instructions) and sent them, and they were in my stateroom when I arrived. I also shipped formula and a suction pump to the resort where we stayed at Disney World.

• Don’t leave anything to chance. When we got to our Disney World resort, the formula was not in our room. I called guest services and was told they would check on it. In the morning, since it was late. When I told them it was an immediate need and why, they located the formula and had it delivered within fifteen minutes.

Airport Security

Going through security was not a pleasant experience. But, at least for me, going through security has greatly improved. Here are my suggestions to make airport security screening go more smoothly:

• Go with a good attitude.

• Wear shoes that are easy to get on and off.

• Have a doctor’s letter stating that your carry-on medical equipment and supplies are medically necessary.

• If you must carry water, as I do, speak to a security representative before you let go of the water. Explain, don’t confront. If necessary, ask for a supervisor. Carry only unopened bottles.

• I carry my ventilator in my lap. It always triggers a search. Security always drags it out of its bag. Just be ready to speak to security about what you have.

• I always have someone with me and get them an airline gate pass so they can help me right up to the boarding gate. Otherwise, my personal belongings, purse and all, would be sitting out in the open on the conveyor belt while I am pulled aside to go through the screening.

The Destination

Disney has a terminal in the Orlando Airport. In both 2008 and 2009, when I arrived there I was in good hands. Disney has an expectation that their guests’ needs will be met. For example, I wanted to board the bus by using a lift instead of the stairs, and a bus with a lift appeared in 15 to 20 minutes to deliver me to my destination. Even if you are not in a wheelchair, your ability to walk may be limited and when checking in you can let them know you’ll need help. Also, you and travel companions can always stay together.

In Disney World and on the cruise, you are treated as a valued guest. I, with my limitations and needs, was never treated like an afterthought. Serving everyone is a part of the culture.

In the park, amusement rides requiring a transfer out of a wheelchair are identified. There are brochures for visitors with disabilities explaining the accessibility, including the rides, in each section of the park. In 2009 my daughter-in-law had reservations for us at themed dinners and various places all over the park, one being the Polynesian Luau. To get around I could travel the accessible sidewalk, or ride the monorail, the boat ferry, and the busses. When I got there I was comfortable using my feeding tube at dinner. At one restaurant, my then-three-year-old grandson explained to the server I had a feeding tube and would not be ordering.

The Cruise

On the Disney Magic cruise ship, even boarding is smooth. It is barrier-free from the dock to the ship. Once you are onboard, your room host will take care of your room and you for the duration of your trip. The room hosts quickly help with any needs. The activities on the ship are accessible.

The ship medical center includes a doctor and nurse. I should have gone to meet the medical staff, but didn’t. I also should have brought a small bottle of dish-washing liquid, but didn’t. When I asked how I could wash my 60 cc syringes for my formula feeding, I was given a bag of 60 cc syringes from the medical room. The crew solves problems as they come up.

Cleanliness is a ship-wide priority. When you enter a restaurant,
Coping Skills

Have Your Questions Answered

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley’s peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

• (888) 610-3008 will be devoted to HPN (intravenously infused nutrition).
• (888) 650-3290 will be devoted to HEN (tube feeding).
• (877) 479-9666 will be devoted to HPEN consumers in their teens and twenties.

We hope you’ll use this opportunity to improve your quality of life.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

In the airport, have a doctor’s letter stating that your carry-on equipment and supplies are medically necessary.

In the airport, have a doctor’s letter stating that your carry-on equipment and supplies are medically necessary.

Introducing...
Maximize Health!
Thrive’s Guide to Intestinal Care

ThriveRx’s goal is to provide comprehensive care for consumers with intestinal disorders, promoting independence and empowerment through clinical expertise, advocacy and education.

Maximize Health! is a web-based nutrition education program for consumers with intestinal failure. This series will focus on enhancing intestinal absorption and minimizing Parenteral and Enteral Nutrition needs in the Short Bowel consumer. Simply register by emailing to Info@Thriverx.net or, call us at 888-684-7483.

Please join our free webinar “Reimbursement for Home PEN” presented by Jennifer Jaffe, Esq., November 5th at noon EST. For more information please contact Donna Noble at 866-890-5517 or d noble@thriverx.net.

THRIVERx

1-888-6-THRIVER (888-684-7483)
or info@thriverx.net
www.thriverx.net

Volume XXXI, No. 5

(800) 776-OLEY • LifelineLetter — 11
Pain, from pg. 2

prostaglandins, interleukins, chemokines, and different growth factors, to mention just a few classes of molecules. Many of these signaling molecules affect the nerve endings, making them more excitable. A standard stimulus may now elicit a stronger response, which may even lead to the perception of pain while it was barely noticed beforehand.

Non-steroidal anti-inflammatory agents (NSAIDS) like ibuprofen or naproxen may partially reverse this process. These two “pain killers” are part of a class of agents that block the production of prostaglandins, important mediators of inflammation. The limited effectiveness of these medications and their serious side effects have led to the search for more specific medications. Ideally such medication would only influence pain-sensing nerve cells. Recent studies have identified nerve growth factor as a possible specific pain-sensing mediator and clinical investigations show some promise with medications affecting this signaling pathway in patients with chronic pain syndromes.

From Sensation to Perception

Each and every second, a barrage of sensory information floods your brain, informing it—oddly enough, not “you”—about the expansion of your lungs, the beating of your heart, the distension of your stomach, the contraction of your bladder, and much more. Very little of this information ever reaches the point of conscious perception.

Using modern technology with sophisticated imaging techniques, such as functional MRI, researchers have been able to take a “look” into the functioning brain. Stimulation of internal organs typically activates brain structures that are linked to pain, to regulation of the internal bodily “environment,” and to emotion. This may explain the strong link between visceral pain and emotion. Moreover, these centers are activated more or less independently of stimulus intensity. This may provide the basis for the observation that, with the exception of hypervigilance) may increase the pain, while distraction may decrease it. Past associations may give similar symptoms different relevance. Moving to a common example not associated with pain, I may experience rectal filling as a harmless sensation that gets me out of my chair to go to the bathroom. A patient with fistulizing Crohn’s disease and impaired closing muscle function may experience the very same stimulation with a sense of panic.

Perception without Sensation

All of the examples I have used to this point describe a link between a stimulus, such as rectal distension in the last paragraph, and a response. However, things are more complicated. Many patients with chronic pain repeatedly hear judgmental statements that it is “all in their heads.” Ironically, modern science confirms this view as much as it debunks it. Let me explain this apparent paradox.

A group of investigators gave patients uncomfortable visceral distension and examined the responses in the brain with functional MRI. They then linked the painful stimulus to a warning signal, a bit like how the physiologist Pavlov rang a bell before feeding his dog in his classic conditioning experiments. After repeated trials, patients actually reported discomfort soon after the warning signal, even if there was no visceral stimulus. Interestingly, the brain activation, during real distension and with anticipation only, was quite similar. So, yes it is in the head, but it may still feel real!

We are also learning that chronic pain changes brain structure, leaving its physical imprint. This imprint may not be permanent, but it clearly shows the strength of the mind-body connection. These findings may help explain why the removal of the organ where chronic pain originates, or a nerve block that prevents transmission of pain, have only limited success in curing or alleviating chronic pain.

Pain and Intestinal Failure

Intestinal failure can be due to many different disorders, such as massive bowel resections for ischemia or Crohn’s disease or pseudo-obstruction caused by impaired gut motility. While the endpoint, the inability of the gut to meet nutritional needs through absorption of nutrients, is similar, the clinical manifestations may differ, and so do the presence, character, cause, and severity of pain.

For example, chronic intestinal pseudo-obstruction may be due to mitochondrial dysfunction, which often leads to a secondary nerve dysfunction, which in turn may contribute to pain in these patients. Patients with systemic sclerosis, where muscle is replaced by non-contracting fibrous tissue, may also develop pseudo-obstruction. If pain develops, it is mostly due to the progressive intestinal distension that results from lack of intestinal motility. Contrast this to the experience of patients with Crohn’s disease, who may have had many surgeries, with extensive adhesions and intestinal strictures causing intermittent obstruction, which also leads to pain.

The message is clear: since there is no simple and single explanation for pain, we need to individualize our diagnostic and therapeutic approach. What are the options that I as a physician choose from and you as a patient may consider?

Pain and Gut Muscle

Powerful muscle contractions or changes in tone can contribute to symptoms, often described as cramps or spasms. We use a variety of strategies to interfere with intestinal muscle activity. The most commonly used “spasmolytics” are anticholinergics (e.g., hyoscyamine or dicyclomine, commonly sold as Levsin® or Bentyl®, respectively), which are relatively safe but can cause side effects from constipation to dry mouth or even somnolence. Acutely, nitroglycerin, which we use to help patients with chest pain, may also blunt abdominal cramps. However, what you win on one side (less of a spasm), you may loose on the other side, as nitroglycerin often causes headaches.
Small studies also report potential benefit from clonidine (sold as Catapres®) or buspirone (BuSpar®), but the number of patients treated this way is small and side effects or interactions with other medications may limit the utility of these agents. Outside of the spectrum of traditional medicine, we have herbal remedies. Here, peppermint oil is probably the most promising, either as a single agent or in combination remedies.

**Targeting the Nerves**

Some of the newer strategies that are being developed to influence nerves sensing or mediating painful sensations are not yet routinely available. We can however block all nerve activity by using local anesthetics. Some studies suggest a benefit of mucosal lidocaine application (e.g., enemas with lidocaine).

In the section about sensors that produce painful stimuli, I brought up TRPV1, the molecule that senses the heat of spicy peppers. Capsaicin, the molecule responsible for this spiciness, is actually a mixed blessing. Acutely, it burns. But over time, it chemically depletes or even destroys the nerve endings that produce the sensation of burning pain. Thus, we successfully use capsaicin cream to treat chronic pain after shingles. Obviously, this strategy will not work in the gut. But two small studies packaged the capsaicin into gel capsules and reported some benefit over time. Be aware, it will burn at least initially! Cinnamon may actually be a more user-friendly alternative. This spice affects another molecule, TRPA1, that is also preferentially found on pain-sensing nerve endings. Interestingly, cinnamon oil has long been used to treat dyspeptic symptoms.

Some like to be more radical and cut or block the whole bundle of nerves as they travel from the gut to the brain. I have previously described why such approaches have only limited success. They also come with a set of problems and side effects. For those of us who do not want to cut connections but still try to influence information flow to the brain, anticonvulsants may be an option. The use of agents such as gabapentin (sold as Neurontin®) and pregabalin (sold as Lyrica®) has been advocated for neuropathic bowel pain and other pain syndromes. The jury on true efficacy for GI pain is still out. Some studies on GI pain show some acute, but limited lasting effects.

As mentioned earlier, a small group of patients with primary chronic intestinal pseudo-obstruction may have underlying mitochondrial disorders. These patients often suffer from neuropathic pain, as well as pain from bowel obstruction, and they may benefit from high doses of L-carnitine or coenzyme Q10, both of which are available over the counter.

**Targeting Pain Processing**

Moving from peripheral sensation to central processing and perception of pain, we can employ strategies that work centrally. For centuries, opioids (narcotics) have been used to treat pain. They are certainly the most effective pain medication we have to ease severe acute pain. Opioids may also work to improve chronic pain. However, they at times fall short of expectations as they seem to influence how well people feel, but not how well they function. Moreover, narcotics come with their own set of problems, from side effects to dependence and addiction. Not surprisingly, researchers and clinicians are looking for alternatives.

I already mentioned anticonvulsive agents, which also affect the brain. Many patients will hear about the potential use of antidepressants. There...
there are many theories about their potential mechanism of action in chronic pain, and there are many studies investigating the effects. Despite this plethora of information, the overall impact still remains unclear. Tricyclic antidepressants (e.g., amitriptyline, commonly sold as Elavil®) seem to be effective in nerve pain and may help in organ pain, if patients can tolerate their common side effects (which range from somnolence to constipation). Selective serotonin reuptake inhibitors (e.g., citalopram, commonly sold as Celexa®) are now preferred for the treatment of mood disorders, but they have an uncertain track record once it comes to pain. However, remember the bidirectional linkage between mood and pain. So, affecting mood as a cause for or consequence of chronic pain could still be helpful. Lastly, there are serotonin norepinephrine reuptake inhibitors (e.g., duloxetine, sold as Cymbalta®), which have shown benefit in some chronic pain syndromes, but which have not yet been studied in patients with GI pain.

The reciprocal relationship between pain and emotion opens up opportunities for psychologically based treatments. Stress-reduction techniques such as progressive relaxation, biofeedback, cognitive behavioral therapy, and hypnotherapy have all been used in chronic GI disorders. They show promise on scales that measure the patients’ overall sense of well-being, which after all is what matters most. As we are learning about these approaches, we are still not sure whether they truly improve pain or primarily alter the tolerance for distress and pain.

Beyond the Belly

When patients or physicians face abdominal pain, they both typically look for a problem originating in one or several of the organs within the abdominal cavity. The previous sections already demonstrated that such a causal linkage is not always present. Beyond the points I made before, I have to keep in mind that the abdominal viscera are surrounded by other structures, which may also play a role in clinical presentations. Abdominal wall pain is common, can be quite severe, and will be missed if we do not consider it. Shingles can erupt over the abdomen and trigger persistent nerve pain. Spinal compression fractures typically hurt in the back; however, they may radiate to the front, and may become so dominant that patients present with severe abdominal pain. I mention these examples not to confuse things even more, but to show that an open and inquisitive mind may identify problems with a more treatable origin.

Conclusions

Chronic pain affects mind and body. Thus treatment needs to go beyond pain medication only. Our armamentarium has expanded and comes with more options that target different levels, from the initial sensation of a painful stimulus to the cognitive processing of such information. All of us, whether patient or physician, have to remember that chronic pain has often lost its physiologic role as an alarm signal, yet it still alarms us.

This knowledge should guide us as we consider diagnostic testing. The reassurance of yet one more unchanged or negative test comes at a price measured not only in economic terms but also in the context of potential medical harm. An example is the cumulative radiation exposure through repeated CT scans. In many cases, it may be better to shift the paradigm and view pain as a disease in its own rights. We may not be able to “fix” it, but we have more options for treating it.
Contributor News

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

PLATINUM LEVEL PARTNERS
($70,000+)

GOLDEN MEDALLION PARTNERS ($50,000–$69,999)
Coram Specialty Infusion Services
Nutrishare, Inc.
ThriveRx

SILVER CIRCLE PARTNERS
($30,000–$49,999)

BRONZE STAR PARTNERS
($20,000–$29,999)

Emmaus Medical, Inc.
NPS Pharmaceuticals

BENEFACTOR LEVEL PARTNERS
($10,000–$19,999)

PATRON LEVEL PARTNERS
($5,000–$9,999)

BLUE RIBBON PARTNERS
($2,500–$4,999)

CONTRIBUTORS
($1,000–$2,499)

B. Braun Medical

Thank You!

Oley Horizon Society Adds New Member!

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

Felice Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Tom Diamantidis, PharmD
Selma Ehrenpreis
Herb & Joy Enich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
The Grober Family
Valerie Gyurko, RN

Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD

NEW! Doris R. Johnson
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Matarrese, PhD, RD,
CNSD
Kathleen McElmuses
Michael Meduvar
Meredith Nelson
Nancy Nicholson
Rodney & Paula Ohmato, RPh
Kay Oldenburg
Judy Peterson, MS, RN
Clemente Pitzner
Beverly Promisel
Abraham Rich
Gail Egan Sansivero, MS, ANP
Roslyn & Eric Scheib Dabl
Susan & Jeffrey Schesnol
Doug Sedlner, MD, FACC, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSD,
& Gregory A. Thompson MD, MS;
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Rosaline Ann & William Wu

Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share the list of honorees in each issue of the newsletter. A complete list of contributions will be published annually in the January/February issue of the LifelineLetter and in the Oley Annual Report.

Between August 7 and September 30, 2010, gifts were received:

In Memory of
Esther Ann Brown Adler; Floyd Greenman; Robin Lang; and Michael Sidoroff

We appreciate all gifts and kind comments that we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. Thank you!
A gift that changes lives

Soon you will receive an appeal to support the work of the Oley Foundation. With your help, Oley can continue to touch the lives of thousands of consumers on home tube and IV feeding. Please give as generously as you are able.

What Is YOUR Quality of Life Like?

Adult parenteral nutrition consumers, we want your input! If you haven’t filled out the Oley Foundation HPN quality of life study yet, please consider doing so today. You are the one who knows what it is like to live with HPN. You are therefore in a unique position to help the medical field understand the impact it has had on your life. Your answers can also help impact future Oley Foundation programs.

You can download the QoL study from www.oley.org/documents/QoL_Survey_11_09.pdf or call (800) 776-6539 for a copy.

Clinicians and Professionals

We ask you to help spread the word and encourage your adult HPN consumers to participate. We would be happy to send you QoL questionnaires to distribute, with the request that your patients return the completed questionnaires directly to Oley.

All responses will be kept completely confidential. This research project has been approved by Albany Medical Center’s Institutional Review Board (IRB).

Donor Profile: Steve and Leah Atkinson

“For us, the commitment to participate in regularly planned giving to the Oley Foundation wasn’t a difficult one. Oley has become an integral part of our son Jameson’s life, and it’s rewarding to us to be able to contribute to Oley’s ongoing success. And, giving is as easy as participating in our company’s United Way program and designating the Oley Foundation. This is just our way of saying thanks for all that Oley does.”

—Steve and Leah Atkinson