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Living with home parenteral and/or enteral nutrition (HPEN)

On Top of the World

Rick Davis, HEN Consumer

I have been 100% dependent on home enteral nutrition (HEN) for almost three years and have learned that HEN should not inhibit a person from doing whatever they want. When I first needed HEN, I never thought I could resume a "normal" life, especially to do the things I really enjoyed: hiking, biking, skiing and going out with friends. Like many other HEN consumers, I was in pretty bad shape when they first pushed a tube through my nose to feed me.

Life on HEN Tough to Swallow

I cannot swallow because a stroke paralyzed my esophagus. For stroke victims who survive, swallowing problems are not unusual, but within three to six months, most people recover their swallow. Not me. I have gone to swallowing specialists at Northwestern, Columbia and Baylor Universities, in addition to the many neurologists, otolaryngologists, gastroenterologists, speech pathologists, physical therapists, hypnotherapists, acupuncturists, etc., I have seen in my own city. The consensus is that I am at the extreme



Rick "taking a drink" in the Grand Canyon

end of the bell curve of stroke victims with swallowing complications. My stroke hit a bull's-eye in the cluster of brain cells controlling my swallow, in particular, affecting my cricopharyngeal sphincter and the muscles of the esophagus that create the peristaltic-like motion moving food down to the

On Top of the World cont., pg. 10



Fabulous Site for 2004 Oley Conference

The Marine Memorial Club and Hotel (www.marineclub.com) in San Francisco, California, is the site for next year's Oley conference and what a fabulous site it is! It positions us one block from the cable car stop, 5 blocks from Chinatown, and a short taxi ride from the ferry to Alcatraz and Fisherman's Wharf. Away from the hustle and bustle of the city, this quaint hotel is the perfect setting for learning about homePEN therapy.

Oley's guests will occupy the entire hotel, with the exception of one small event taking place during our conference. The room rate of \$125/night includes a complete breakfast each morning and complimentary cocktails from 4:00-6:00 p.m. each evening. We couldn't think of a better opportunity for "lifeliners"

Oley Conference cont., pg. 5

Home Enteral Nutrition

Carol S. Ireton-Jones, PhD, RD, LD, CNSD
Coram Healthcare

The most common home infusion therapy provided today is home enteral nutrition (HEN) or tube feeding. HEN should be used in patients who cannot meet their nutrient requirements by oral intake, yet have a functional gastrointestinal (GI) tract, and who are able to receive therapy outside of an acute care setting. It is estimated that more than 344,000 people of all ages in the US are receiving HEN. The following article will review the indications for HEN, the nutritional considerations in developing the feeding regimen, enteral access and formula selection, and monitoring.

Indications for HEN

Enteral nutrition support can be accomplished in a wide variety of patients with many disease processes, from dysphagia to short bowel syndrome. Often quoted is the phrase, "if the gut works, use it." A minimum of 100 cm jejunal and 150 cm ileal length of functioning small bowel, with the ileocecal valve intact, is necessary for sufficient absorption of nutrients in the GI tract. Patients with high output fistulas, or severe nausea, vomiting or diarrhea are probably not candi-

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Enteral Nutrition, from pg. 1

dates for enteral feeding. In addition, no mechanical obstruction of the GI tract or GI hemorrhage should be present.

Discharging a Patient on HEN

When a patient is identified as a candidate for HEN and a tube is inserted, education for the patient, and caregiver should be initiated. Because of shorter hospital stays this may be

done primarily at home. The patient and caregiver's ability to be trained and perform the tasks associated with HEN, reimbursement for HEN and the home environment, should be evaluated prior to sending a patient home as these are important determinants of the success of HEN. A qualified HEN provider should be selected by the physician in coordination with the discharge planner and patient/caregiver. The HEN provider may be a home care company, home infusion company or a DME (durable medical equipment) company. It is important that the HEN provider for supplies (and potentially nursing and nutrition services) is introduced to the patient and caregiver, prior to discharge, if possible. Often when the patient is referred, the HEN provider is given the patient's name, age, diagnosis and enteral feeding order. If the patient or family has been trained on enteral feeding techniques in the hospital, the HEN provider may simply supply product and appliances (bags, tubing, pump).

Nutrition Assessment

Prior to initiating enteral nutrition, it is important that a patient receive a nutrition assessment to determine his or her nutritional status and therefore nutrient needs. The American Dietetic Association defines a nutrition assessment as, "A comprehensive approach, completed by a registered dietitian, to defining nutritional status that uses medical, nutrition, and medication histories; physical examination; anthropometric measurements; and laboratory data. Further, it includes the organization and evaluation of information to declare a professional judgment." Objective measurements of nutrition status include biochemical measurements of serum proteins, electrolytes and other chemical indices. Subjective analyses include evaluation of nutritional history for weight, appetite, and dietary intake changes, presence or history of GI symptoms/problems, functional capacity, and physical symptoms of nutritional deficiency such as a wasted or cachectic appearance. A nutrition assessment may be conducted in the hospital prior to discharge, in the physician's office or in the home. The nutrition assessment may also be done from a telephone conversation with the patient or caregiver after he/she has arrived home.

Nutrient Requirements

Energy and protein requirements are determined based on the patient's nutritional and

medical status. Energy requirements are most often estimated from energy equations. Most individuals require a range of 20-35 kcal/kg of body weight/day. Protein requirements usually range from 1.0-1.5 gram/kg body weight/day, with modifications (seldom >1.5 g/kg body weight/day) to account for increased needs due to healing wounds, or acute or chronic disease. If a patient is malnourished, nutrient needs may be greater at first to restore nutritional status. Adequacy of wound healing and return or improvement of physical strength may be useful indicators of restored protein status in the person receiving HEN.

Fluid requirements must be determined, and then provided daily to the patient through the formula and other sources. Fluid needs are calculated for adults and children as follows:
Adults: 35 ml/kg body weight/day

Children:

- 100 ml/kg/day for the first 10 kg body weight
- add 50 ml/kg/day for the second 10 kg body weight
- For each additional kg of body weight add 20 ml/kg per day.

Most "standard" 1 kcal/ml enteral formulas contain about 80% water so a patient receiving 1500 kcals would receive 1200 ml of water from the formula. If the patient weighs 60 kg, he needs an additional 700 ml of water each day. It is important to account for other fluid losses from fever, diarrhea and vomiting, and to provide additional fluid replacement to meet these needs. Failure to account for fluid needs can lead to dehydration and rehospitalization. For the most part, enteral formulas contain 100% of all vitamins and minerals required when at least 1000 kcals are taken each day. Infrequently, a vitamin and mineral supplement or specific nutrients may be added to compensate for a nutritional deficiency, but this is uncommon. More frequently inadequate nutrition in HEN patients is due to inadequate infusion, which is why careful monitoring is important.

Enteral Access

Successful HEN is dependent upon a reliable, low-risk, comfortable method of enteral access. Frequent or prolonged interruptions in therapy related to enteral access are frustrating for patients, caregivers, and clinicians. Well thought out decisions about the type and location of enteral access are necessary to minimize complications. In determining the type of enteral access to be used, the physician

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Subscriptions:

The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

* * * * *

The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Director of Publications & Information at the address above.

Nutrition Week 2004: A Peek Into the Future!

You are invited to the first-ever congress in Las Vegas, Nevada, where specialists from around the world will develop the agenda for future research on intestinal failure. This is a unique and exciting opportunity! We are strictly a listening audience, but there is a wealth of information to learn and Oley can get answers to your questions from speakers at a later date.

Funded by NIH, the program is entitled "Intestinal Failure: Current and Emerging Therapies Including Transplantation," and takes place on February 7-8, 2004, from 8 a.m. to 5 p.m. Oley members wishing to attend must make reservations and pay the \$50 fee, through Oley, prior to January 9. Sign up online or call the office at 800/776-OLEY. Be sure to ask about details on room rates (\$45-\$65/ night), volunteering at the Oley Booth, and the one-day exhibit hall pass.

Highlights from the program are outlined below. More details will be posted on our website, www.oley.org. We can't get any closer to the cutting edge than this! We hope to see you — Viva Las Vegas!



Research Program: Saturday, February 7th

Intestinal Failure in Children and Adults

- Etiology, Initial Mgmt of Intestinal Failure in Adults/Children
- Motility Disorders: Specific Issues in Assessment and Management

Longterm Parenteral and Enteral Nutrition

- Guidelines for Management of HomePEN
- Home Nutrition Support: Survival, Cost and Quality of Life
- Efficacy of Specialized Nutrition Formulas

We Have a Winner!

Congratulations to Mary Lou Yetto of Troy, New York, the lucky winner of the Oley Quilt! Mary Lou is a friend and neighbor of homePN consumer and Oley volunteer, Joyce Hydorn. We thank Mary Lou, Joyce and everyone else who bought and sold raffle tickets. And of course, a big thank you to everyone who made a quilt square and to the Weavers for stitching it together. We appreciate your support of Oley programs!

Anyone who quilts, knits, makes jewelry, or any craft, is encouraged to donate items to Oley. You can also be creative in other ways; do you shop somewhere regularly or have connections at a business that might donate a big ticket item like electronic equipment, airfare, an overnight stay at a hotel? Could you spare a few days or a week at your vacation home or condo?

Proceeds from the raffles and auctions help support Oley's outreach and educational efforts. Every dollar helps! Our usual auction venue is held at the annual conference, but if enough items are gathered, we would consider an coordinating online auction like eBay.

Raffle and auction items can be sent along with a note detailing who to thank and approximate value, to the Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208. Any questions? Contact Joan Bishop at bishopj@mail.amc.edu or (800) 776-OLEY / (518) 262-5079. ©

Chronic Complications and Clinical Management

- Intestinal Failure Associated Liver Disease: What Do We Know Today?
- Bacterial Overgrowth: Role of Antibiotics, Prebiotics and Probiotics
- Access-Related Complications: Maintaining Patency/Alternate Sites

Novel Agents in the Treatment of Intestinal Failure: Luminal Factors

- Mechanisms of EN-Enhanced Intestinal Function
- Short-Chain Fatty Acid Enhanced Intestinal Adaptation
- Glutamine: Does the Data Support the Cause?

Sunday, February 8th

Novel Agents in the Treatment of Intestinal Failure: Humoral Factors

- Recent Clinical Outcomes with IGF-I/Growth Hormone
- Intestinotrophic Growth Factors: EGF/TGF/KGF
- Glucagon-Like Peptide-2: Update of the Recent Clinical Trials

Intestinal Transplantation: Who? What? When?

- Is There A Role for AGIR Procedures in an Era of Transplantation?
- Patient Selection, Referral to Comprehensive IR Unit or Transplantation
- What Procedures are Best Suited for the Individual Patient?
- Innovative Approaches to the Organ Donor Shortage

Intestinal Transplantation: Outcomes

- Post-Transplantation Patient and Graft Survival
- Intestinal Transplantation: Cost and Quality of Life
- Optimal Management of the Post-Transplantation Patient

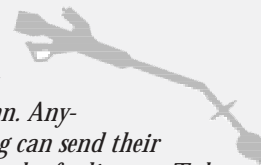
Future Directions

- Relevant Research Aims and Experimental Models
- Summary and Directions for Future Investigations



Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their 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 DahlR@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.



Device Crushes and Administers Meds

If grinding up meds is problematic for you, here's one alternative to a mortar and pestle. Known as the HandyCrush, it is a syringe that allows the user to crush tablet medications, draw up water, and administer the medication — all with one device. The HandyCrush is made by the Welcon Company and available through most major home health care and durable medical equipment (DME) distributors. Prices will vary in retail, but the average wholesale price is 33 syringes for \$49.

Lifeline Mailbox

HomePEN in the Movies

In the recently released movie, *Intolerable Cruelty*, produced by the Coen brothers, and starring George Clooney and Catherine Zeta-Jones, there are two scenes involving what must be homePEN. Clooney is a junior fellow in a law firm, and on two occasions he is summoned to appear before the senior partner of the firm, Tom Aldredge. Aldredge is an old curmudgeon, having devoted his whole life to making money, and is now so old and infirm he exists on what appears to be tube feeding. In both scenes, Aldredge is surrounded by IV poles with mysterious looking bags dangling from them, and there is a half inch plastic tube protruding from his chest. He is also on oxygen, and in the movie, the comment is made regarding Aldredge "when you have a colostomy, who needs a home?" Obviously someone either directing or writing the

film had some experience with folks like us— though we are not so infirm, curmudgeonly, or rich as the character, Aldredge, in this film.

— Donald Empson
Stillwater, MN

Missing 'Time Life' Book

Lee & Marshall Koonin, founders of the Lifeline Foundation and *LifelineLetter*, gave an inspirational talk at the 2003 Oley Conference in St. Augustine, complete with a video and other early publicity materials about Lee and Foundation. They generously shared these materials, including a Time Life book that describes Lee's early years on homePEN. Unfortunately, the Time Life book was lost in the shuffle. If anyone got hold of the book and has it in their safe keeping, please call the Oley Foundation at (800) 776-OLEY or email DahlR@mail.amc.edu. Thank You! ☺

Oley Cookbooks — the Perfect Gift!

A collection of wonderful recipes, highlighted with a few of our favorite snapshots and information about Oley, are the perfect gift for everyone! The cost is \$10.00 each, plus \$2.50 shipping and handling. Order copies today for yourself, your family, friends — even a favorite clinician!

We're guessing with the Christmas mail rush that this newsletter may arrive late, BUT just in case it isn't, **Special Delivery** is available for the holidays. Let us ship your books/gifts from here. We'll insert the greeting of your choice and send the book directly to your favorite cook! **For Special Delivery, be sure to call Oley by December 20.** (Be sure to visit www.oley.org frequently for the latest news from Oley!) **For all non-rush orders**, complete the form below and send it with your check made out to "The Oley Foundation" A huge thanks to Dava Huss for organizing, categorizing, and sorting our recipes. We're extremely grateful! ☺



Order Form

The Oley Foundation • 214 Hun Memorial, MC-28
Albany Medical Center • Albany, NY 12208
(800) 776-OLEY/(518) 262-5079 • www.oley.org

# Cookbooks	Each	Total Amt.
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*Price includes shipping and handling within the continental U.S. Please call about any special order requests.

Please make checks payable to "The Oley Foundation."

Ship To:

Name

Address

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() -
Daytime Phone

@
Email

Equipment Exchange

The following supplies and equipment are offered free of charge to *LifelineLetter* readers:

EN Formula

- 3+ cases Two Cal HN

Bags/Tubing/Administration Sets

- 12+ Kangaroo bags
- 3 boxes Kangaroo 1000 ml bags
- Many cases Kangaroo 500 ml bags
- 32 Kangaroo bags 1000 ml
- 2 Ross G-tube Kits 14 Fr.
- 15+ Bous Mickey extension tubes
- 9 Baxter Solution Sets
- 28 Zevex Enterlite 1200 ml sets
- 4 Zevex Enterlite 500 ml sets
- Foley Catheters 10 fr 30 cc/18 fr. 5 cc, #D11554/D1166IP
- Curly tubing 200 cm and 100 cm, #1159.70/1159.60
- 8 Minibore non DEHP ext sets. 0.28 ml, AMS 395-1
- 13 microbore ext sets 7" 0.6 ml, AMS 520
- 2 B. Braun multi-ad fluid transfer sets, #513548
- 16 CADD TPN Admin. Sets w 0.2 u filter, #21-7085

Equipment/Miscellaneous Supplies

- 1 IV Pole
- 2 Stat lock catheter securement devices
- Surgilast elastic dressing to hold g-tube
- Misc. TPN supplies, connectors, dressings, syringes, tape etc.

WANTED: Reliable, portable TPN pump and tubing for family in India

MORE SUPPLIES are available! For a complete listing, visit our website at www.oley.org or contact Cathy at HarrinC@mail.amc.edu, (800) 776-OLEY. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods offer to pay for shipping — especially for heavier items such as formula or pumps. ☺

In Memory of Diane Kane

Diane Kane, 47, longtime Oley friend and Regional Coordinator from Lecanto, Florida, died this October. Diane battled dysmotility and gastrointestinal disorders for more than 20 years. She was a fighter and a firm believer in living life to its fullest; these qualities shone through in her efforts to bring homePEN support and outreach to her community. Her contributions were immeasurable.

Diane's husband, Gary, predeceased her 11 months ago. Along with their beloved children Heather and Robert, Diane and Gary will be remembered for their inexhaustible technique for gathering friends and acquaintances at Oley conferences and will be truly missed.

As we mourn the passing of one of our "family" members, we should remember to keep Heather and Robert in our thoughts as they adjust to their tremendous loss and attempt to move forward. ☺



Diane Kane

Bright Ideas

Do you have any bright ideas about tube feeding or TPN? Anything small or large that improves your quality of life, cuts costs, keeps you healthier?

Any ideas are welcome, but to get your creative juices flowing, we'll solicit tips on certain topics each issue. For this edition we are collecting suggestions on swimming safely and discreetly.

Send your tips to the LifelineLetter Editor: DahlR@mail.amc.edu or Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208. Ideas will be published in the newsletter and posted on Oley's website (www.oley.org) as space permits. Photos or illustrations are welcome. Be sure to include your name, city and state, daytime phone number and what therapy you are on. ☺



Oley Conference, from pg. 1

and their families to have access to clinicians and others who survive in a similar fashion. Whether you prefer to enjoy a quick moment with each other in the hallway, hold a brief consult during breakfast, share a concern over cocktails in the evening or simply relax amongst friends in this lovely setting overlooking San Francisco, you are bound to walk away empowered!

Although it's early in the planning phase and we cannot outline the entire program we can promise to set the stage for a great educational opportunity. The endoluminal brush will be discussed as an option for clearing occluded catheters as well as a tool for diagnosing infections. Aluminum exposure in parenteral nutrition is a "hot" topic and on the list of featured presentations. We're also planning sessions to cover school advocacy and Catheter Care for Ultimate Success. So mark the dates June 29-July 2, 2004, in your calendar and keep watching the newsletter and website (www.oley.org) as the details unfold. ☺

Ongoing Research Trials

• Research on Swallowing Problems

Researchers at the National Institutes of Neurological Disorders and Stroke, NIH, are studying Swallowing Disorders. The purpose of these experimental studies are to develop a new method for helping individuals with life threatening swallowing problems and to determine if muscle stimulation can reduce choking in individuals with swallowing problems. For more information, please call (301) 496-9367 or (800) 411-1222.

• Short Gut TPN Patients Wanted

Dr. Thomas Ziegler is researching the effects of modifications in oral diet, with and without treatment with synthetically-derived human growth hormone, on intestinal nutrient absorption and clinical outcomes in TPN-dependent SBS patients. For more details, contact Dr. Ziegler at 404-727-7351 or tzieg01@emory.edu.

Both of the research studies listed have been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee, however, ***The Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.***

More information on these studies is available by calling (800) 776-OLEY or visiting our web page at <http://www.oley.org/news/researchbox.html> If you are interested in having your research study listed, complete the form listed on Oley's web page OR fax the same information to (518) 262-5528.



"Nutrishare treats the whole person, and I should know. After receiving my Master's Degree, I now teach nursing at Indiana University."

- Phyllis Mooney

Nutrishare, Inc.

1-800-HOME TPN

Nutrishare scored an unprecedented 100% on its latest ACHC accreditation survey.

Enteral Nutrition, from pg. 2

must consider how long the patient will receive the enteral feeding (short or long term) as well as the type and viscosity of the feeding solution, volume of solution to be provided and the administration rate.

There are five placement methods for enteral access devices: nasally placed tubes which may end in the stomach, duodenum, or jejunum; the other tubes are located in the stomach or jejunum and placed surgically, endoscopically, laparoscopically, or radiologically. Each of the placement techniques has pros and cons and they differ in their suitability for long vs. short-term therapy. The physician and patient should discuss these options prior to the placement of a feeding tube.

Length of Therapy

Nasogastric or nasointestinal tubes are most suitable for short-term therapy (< 6 weeks). These tubes can be placed in an outpatient or

home setting; however, their position should be confirmed radiologically after insertion to ensure proper placement. Nasally placed tubes aren't used often for HEN, but they can be used with caution for patients who are meticulous in recognizing and reporting possible tube displacement, and are often the preferred approach in small infants.

Surgically, endoscopically, laparoscopically, or radiologically placed tubes located in the stomach or jejunum are recommended for long-term (> 6 weeks of therapy) or lifetime HEN. They are less likely to become displaced than nasally placed tubes. Signs of displacement include a change in the length of the external portion of the tube, difficulty in infusing or flushing, leakage of formula or flush solution from the exit site, or a stationary tube that is painful.

Feeding Site

The level of gastric function, and the risk of aspiration determine the feeding site. Duodenal

or jejunal feeding allows patients with impaired gastric emptying to be fed safely. Aspiration risk is believed to be higher for patients with impaired gag reflex, altered level of consciousness, prior history of aspiration, and known alteration in gastroesophageal reflux, and therefore duodenal feedings may be preferred.

Selection of Formula

Functional status of the GI tract and absorptive capacity are the predominant factors in choosing a formula. Other considerations include: nutritional status/medical therapy; renal function; fluid tolerance/electrolyte balance, and route of delivery. Formulas are categorized according to their type and amount of protein and calories; some are tailored for different disease states. It is important for a registered dietitian to be involved in the selection of formula and substitution of a product, if necessary.

As the science of nutrition has evolved, so too, has the development of formulas. Standard formulas are now available that can meet

Table 1: Common Physiologic Complications of HEN

Complication	Possible Causes	Prevention/Therapy
Diarrhea/cramping	Drug therapy including: antibiotics or diarrhea-inducing meds Fat malabsorption Formula administered too cold Microbial contamination Infusion rate too rapid Hyperosmolar formula Hypoalbuminemia	<ul style="list-style-type: none"> • Review meds with pharmacist and identify meds with causative agents (sorbitol-elixirs, magnesium, or laxatives). • Repopulate normal gut flora with commercial lactobacillus granules. • Administer antidiarrheal medication as indicated. • Consider low fat or MCT containing formula. • Administer formula at room temperature. • Assure that clean technique is used for preparation/ administration. • Culture for <i>C. difficile</i> if on antibiotic therapy. • Modify infusion rate to decrease. • Dilute formula initially or decrease infusion rate. • Change to compatible formula with lower osmolality. • Consider peptide formula until absorptive capacity of GI tract improves. • Initiate at low rate and increase gradually as tolerated.
Constipation	Inadequate fluid intake/inactivity/ medication	<ul style="list-style-type: none"> • Increase fluids or assure that adequate fluids are being infused. • Use fiber containing formula or add fiber to feeding. • Consider laxatives or stool softeners.
Nausea, vomiting	Gastric retention Rapid infusion of formula or volume too large	<ul style="list-style-type: none"> • Consider small bowel feeding. • Consider prokinetic agents. • Small bowel feeding. • Maintain head of bed at least 30°.
Abdominal distention, gas, bloating, cramping	Rapid infusion of formula Adjustment to feedings Nutrient malabsorption	<ul style="list-style-type: none"> • Modify rate of infusion (use lower rate and gradually increase as tolerated). • Assure that air is removed from tubing before connecting set to tube and that tube is clamped when not in use. • Consider lower fat formula, formula composed of hydrolyzed nutrients.
Dehydration	Inadequate fluid intake Increased fluid loss from diarrhea, vomiting, or gastric drainage	<ul style="list-style-type: none"> • Assess fluid status. • Increase or supplement fluid intake as required. • Refer for treatment of GI condition.

the needs of most patients. To avoid lactose intolerance, the majority of enteral supplements and formulas are lactose-free or contain only a trace amount of lactose. Most formulas contain whole protein and are used for patients with a GI tract that is able to digest and absorb intact proteins. Standard whole protein formulas can be flavored or unflavored. Unflavored formulas are usually isotonic (concentration of all nutrients in the formula is the same as the concentration of the blood, approximately 300 mOsm/kg water). Isotonic formulas are well tolerated, but products with osmolarities greater than 300m/kg water may draw water into the GI tract, causing diarrhea. The addition of flavoring to enteral formulas enhances the taste, but at the same time, usually increases the osmolarity of the solution.

High calorie or calorically dense formulas provide 1.5-2.0 kcal/mL and are used for patients who have elevated calorie needs (ranging from 25-35 kcal/kg) or require fluid restriction. High protein formulas are designed for patients with increased protein requirements, or normal protein, but reduced calorie, requirements. These formulas usually contain 20-25% of the calories from protein as compared to 14-16% of calories from protein in standard formulas.

Fiber containing formulas are useful in patients requiring bowel management. Fiber can help manage diarrhea by absorbing excess water from the stool, and can help manage constipation by providing bulk to the stool. Soy polysaccharide is the fiber most often used in formulas and it contains 95% insoluble and 5% soluble fiber. The soluble fiber provides benefits in blood glucose control, management of blood lipid levels, and can be fermented to short chain fatty acids which are a fuel for the colonic lining cells.

Elemental diets are for patients with a GI dysfunction impairing their ability to digest and absorb nutrients. In these diets smaller molecules called peptides replace whole proteins. The carbohydrate source is usually glucose in the form of glucose oligosaccharides or maltodextrin. Fat is provided from a blend of medium chain triglycerides (MCT) to enhance fat absorption and polyunsaturated long chain triglycerides (LCT) to prevent essential fatty acid deficiency. There are elemental formulas available that are isotonic which makes them easier to tolerate.

Sometimes, but not often, specialized formulas

may be necessary if there is specific organ dysfunction. Disease specific enteral formulas are available for patients with pulmonary, renal and hepatic disease. These should be used under the close supervision of the clinical team with careful monitoring of outcome.

Reimbursement

There are three ways a patient may pay for HEN: through their insurance company, a government insurance program such as Medicare or Medicaid, or out of their own pocket. Insurance companies (also called “payors”) vary in what they will reimburse for HEN based on the employer’s requests when the insurance is purchased. Often, payors reimburse for the feeding tube, enteral pump and feeding supplies, but not for the enteral formula, which they consider “food” that the

patient would be purchasing routinely. Medicaid reimbursement varies and is determined on a state-by-state basis. Medicare does reimburse for HEN; however Medicare recipients must be enrolled in Medicare Part B and meet stringent criteria. For Medicare patients, documentation of permanence, diagnosis and other factors are required to initiate HEN, and extra documentation is required for specialized enteral feedings such as disease specific or elemental formulas.

Complications of Enteral Nutrition

The complications associated with HEN fall into one of two categories for the most part: physiological or mechanical. Physiological complications have to do with the patient’s intolerance or adverse reaction to the formula,

Enteral Nutrition cont., pg. 8

Table 2: HEN Consumer Monitoring Checklist

My enteral formula: _____
 My administration schedule: _____

(what time of the day do you like to receive the feeding, how much and how)
 My goal weight: _____
 Contact numbers: Physician: _____
 Home care provider: _____

Daily Records							
Item/Date	Mon.	Tues.	Wed.	Thur.	Fri.	Sat.	Sun.
Weight							
Intake of formula (ml)							
Intake of water (ml)							
Diarrhea* y/n, # of episodes							
Vomiting* y/n, # of episodes							
Constipation* y/n							
Activity level** (same as usual, less, more)							
Changes in meds+ y/n (note change)							
Hospitalization+ y/n, reason							
Notes							

*If any of these last 3 days, or are severe, contact your clinician
 **If activity level changes for a continued period, contact your MD as your kcal needs may change.
 +Alert my home care provider and physician of any changes in medications or hospitalization.

For a larger version of Table 2, visit www.oley.org OR enlarge it with a copier machine

Enteral Nutrition, from pg. 7

whereas, mechanical complications are mostly associated with the tube or equipment. The Oley Foundation's HEN Complication Chart is a valuable tool for patients, caregivers and clinicians, and is available by calling 800/776-OLEY or 518/262-5079.

Mechanical complications of enteral access devices include displacement, occlusion, and breakage. Displacement of naso-gastric or intestinal tubes can go unrecognized by caregivers and patients, and pose the risk of unintended administration of the formula into the nasopharynx, esophagus or peritoneal cavity. Patients and caregivers should learn techniques to detect tube displacement, such as measuring and marking the length of the tube outside of the patient's body, and should check for tube displacement prior to administering formula. They should also learn to recognize situations in which the tube is likely to become displaced, such as violent coughing, vomiting, and accidental tugging on the tube. Patients with nasointestinal tubes should report vomiting of tube feeding formula to his or her physician.

Most long-term enteral access devices have

replacement end adapters for leaks or breakage. Home care clinicians should carefully document the type, brand, and size of permanent feeding tubes, and develop a plan for replacement or repair of the tube with the family should breakage occur.

Occlusion of the tube is better prevented than treated. Primary factors that may contribute to occlusion (blockage) include the use of small bore tubes for medication administration and inadequate flushing. Putting anything into the tube that has not been recommended or reviewed with the home care team should be avoided. The patient may be able to digest home cooked food, but the size of the tube may make that option almost impossible. Any "approved" food item should be completely blenderized and then strained through a medium strainer before being instilled into the tube. If at all possible, medications should be administered via another route or be provided in liquid form. Crushed pills and fiber containing laxatives should not be given via the tube or in the feeding bag. Substances that are added to the feeding formula increase the risk of tube occlusion (blockage).

Water is the best flush solution. Often, patients who receive HEN do not receive

adequate amounts of free water (water not in the formula). Unless fluid is restricted, most patients should flush their tubes frequently with a liberal amount of water (60 to 120 ml) and infuse additional free water to meet his/her daily fluid requirement.

One of the most common complications after surgical gastrostomy, percutaneous endoscopic gastrostomy (PEG) and radiologic gastrostomy, is infection around the wound exit site (or abdominal wound following surgical gastrostomy). The tube exit site and abdominal wound, if present, should be carefully assessed for edema, erythema (redness), drainage, or necrotic material. Patients should care for the tube exit site using the method described by the physician when the tube is newly placed. Mild soap and water can be used to cleanse around the tube exit site once it heals. Patients should clean carefully under the external portion of their tube to remove debris and to check for excessive pressure. In most cases, it is better to avoid placing a dressing over the site once it has healed. Leakage of gastric secretions around the site is usually corrected by tightening, though sometimes by loosening, the external bolster. A bolster that is too loose permits leakage; but

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one that is too tight poses the risk of internal pressure necrosis, and distorts the exit opening, which also permits leakage. Granulation tissue that forms around the site may require cautery with silver nitrate sticks to prevent bleeding and scabbing. With the physician's prescription topical Lidocaine (2 % solution) can be used prior to cauterization to keep the patient comfortable. Patients should report any drainage, pain, bleeding, swelling, or irritation at the tube exit site to their physician.

Aspiration risk should be considered when determining where to place the tube. Aspiration can be avoided by using appropriate feeding techniques, including elevating the head of the bed at least 30° during, and for at least one hour following, the tube feeding. (Note: Put head of the bed on 6" blocks for feedings taken in bed. Feeding while sitting up or using wedge pillows increases intra-abdominal pressure and can aggravate reflux.)

Physiological complications revolve around GI intolerance manifested as nausea or vomiting, diarrhea, or constipation (Table 1). Such things as inappropriate formula administration, lactose intolerance, or drug therapy may cause these GI symptoms. Many medications are hypertonic and may cause diarrhea if given at the same time as an enteral formula. If these symptoms occur, the patient or caregiver should contact the physician or home care clinician.

Monitoring

Although most HEN patients are seen only occasionally by the primary physician or when a problem arises, monitoring at regular intervals is necessary to ensure the nutrition regimen is working. Some of the problems encountered by HEN patients include: poor understanding of the feeding regimen; inadequate administration of free water; too many or too few bag changes; significant, but unrealized weight changes; exacerbated bed sores; and inadequate feeding regimens. These types of problems can only be uncovered if a qualified home care clinician or health care professional is monitoring the HEN patient.

In home care, subjective measures of nutritional status such as evaluation of daily intake and body weight changes reported by the HEN consumer can be the most useful data in ongoing monitoring of home enteral therapy. Body weight is useful to monitor nutritional status unless the patient is bed-bound and cannot be weighed. In these cases, a follow up home nutrition assessment is useful to identify signs of skin breakdown or deterioration. For children receiving enteral feedings, an appropriate growth rate would indicate the nutrition regimen is adequate. On-going communication between the home care clinician and the patient or caregiver is important to assure that the feeding regimen is adhered to and is appropriate for the patient as time progresses. Some patients may require daily telephonic follow-up when beginning HEN, then progress to weekly and then monthly contact, where a long-term, stable patient may require follow-up only quarterly or twice per year. Table 2 lists some suggestions for HEN patients to use in monitoring their own progress.

HEN is an effective, relatively safe and common method of providing life sustaining nutrients to someone who cannot adequately consume nutrients orally. Proper planning, patient education and monitoring is needed to assure success. This can be accomplished by the physician and hospital or ambulatory setting care team working in tandem with the home enteral provider's multidisciplinary health care team. ©

This article is a revision of an article written by the author and Marsha Orr, MSN, RN, and Kathy Hennessy, MSN, RN. References and/or a bibliography are available upon request.

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On Top of the World, from pg. 1

stomach. I've had scopes down my throat more than a dozen times; eight injections of botox punched through my larynx to relax my spasmodic sphincter; months of swallowing exercises done up to twelve times daily; all to no avail. Thank goodness for HEN.

The stroke also affected my right side and my balance. At first I could not stand up without help. Slowly, I learned to use a walker. My goal was to shuffle to the end of the hall by the time I was discharged from the rehab ward — a small victory! At home, I walked every day. After a few weeks, I made my goal of walking to the end of the block and back, unassisted. After several months, I reached more goals: walking a mile, then several miles. Another goal was to ski again. Four months after my stroke, I tried to ski, but could not. It was depressing. The next year, I was stronger and learned to ski at the National Ability Center at the Park City Ski Resort. A year ago, I tried to hike the Grand Canyon, but could only go part way. This year, I am stronger and made it all the way across. We hiked from the north rim to the south rim in one day — 23.4 miles, plus a mile down and then a mile up. It has taken awhile, but working toward goals has helped me move forward.

Tube feeding has had a similar slow progression from "pretty awful" to "not bad at all." At first, I had a hard time tolerating enteral feeding, with severe reflux, vomiting and cramps. I lost nearly forty pounds, going from "stocky" to "gaunt". My friends thought I was going to die. I was extremely fatigued, sleeping twelve to fourteen hours a day, and had absolutely no energy when I was awake. My fingers were callused from opening those little 8 oz cans, and I thought I would get carpal tunnel syndrome from grinding up my meds with a mortar and pestle so I could dissolve the powder in water and inject it. My PEG tube dangled about three inches down my stomach and the stoma hurt whenever I caught the tube on something, or rolled over in my sleep and jerked the tube. Because I could not even swallow my own saliva, I had to constantly spit into a cup. I was miserable.

Change for the Better

Two things turned me around. Six months after my stroke, my neurologist prescribed an antidepressant. I was as much physically depressed as I was emotionally depressed. Soon, I had enough energy to walk more frequently and life did not seem so bleak.


The second thing was the Oley Foundation. After awhile, most of the health care professionals working with me had lost interest in my case; but, my home care nutritionist, Stacie Carbine, RD, CD, kept following up (even though I was angry and rude — she is an angel!) and gave me a copy of the *LifelineLetter*. Eighteen months after my stroke, I attended the Oley Conference in Anaheim. What an eye-opener! It was great! I met people who had gotten on with their lives, in spite of having a tube in their tummy. I learned about a low profile MIC-KEY tube that did not dangle and get caught, jerking my stoma. I found out that Jevity came in big plastic jugs and there were things called spike sets. Wow! I didn't have to open a bunch of little cans and wash out bags and tubes anymore. A GI doctor told me about Robinul, a prescription to reduce my mucous and saliva, so I did not have to spit all the time. I discovered a portable pump so I could feed while I walked, instead of sitting for hours under an IV pole. I learned that if you keep appealing decisions made by social security disability bureaucrats, that eventually you will find someone with common sense who will make the right judgment. I met people who really care about helping other people. I was so grateful for the experience.

I had planned to attend the conference in St. Augustine this past summer, but eighteen days before it started, I had surgery to repair a shattered collarbone and broken arm. The good news is, I had recovered well enough to ride my mountain bike. The bad news is, I flew over the handlebars at a blind corner to avoid a collision and, instead of doing a shoulder roll when I hit the ground, I did a shoulder crunch. But, I will be at the Conference next year.

In terms of day-to-day HEN management, I'm a lucky guy. I'm 60 years old, 5' 8" tall and weigh 152 pounds. I can control the calories I take in to balance the calories I burn. If my weight goes over 155, I cut back on my feedings and calories. If I go below 150, I just increase my caloric intake. I do not experience hunger or thirst. The frequency I need to urinate and the color of my urine, tell me how often and how much I need to hydrate. I can tolerate a long time between feedings. Usually, I gravity feed one liter of Osmolite (1000 calories) first thing in the morning. Apparently, I'm not hypoglycemic (blood sugar is normal) because I can go until evening (14 to 16 hours) before a second feeding at the end of the day, pump feeding 1.5 liters of Jevity Plus (1800 calories). That is especially good during the ski season; because I don't have to stop for lunch, I can get a maximum number of runs each day. Last year, I skied 65 days, taking 1,062 runs and going down 1,202,000 vertical feet. Goals are good and measuring your performance can remind you how much you've accomplished.

Thanks in part to the Oley Foundation, my life is good. I can hike and ski. I can go out to dinner with family and friends; I just don't order. My wife and I can travel (when this goes to press we will be on a five week trip to New Zealand). Having a tube in my stomach and doing HEN is not a reason to slow me down. I learned that others have done it and so can I. So if you are new to tube feeding and struggling with it, like I was, I hope this story encourages you to keep reaching for a better quality of life. ☺

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Toll Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the US and Canada. Two toll-free numbers are circulated to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Regional Coordinators with a better grasp of their region's needs.

Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 30 minutes.

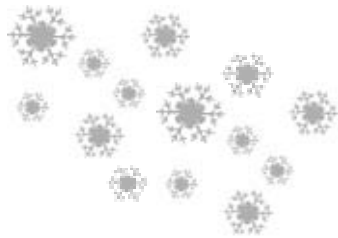
The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted on our web page @ www.oley.org. Comments? Call (800) 776-OLEY.

JAN. '04	<p>Eleana Shore West Hills, CA (888) 610-3008 PST</p>	<p>Eleana's daughter Erin (age 7-1/2) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, Arthritis and Hypomotility disorder. She has undergone three Nissen Funduplications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.</p>
	<p>Eleanor Orkis Schenectady, NY (888) 650-3290 EST</p>	<p>Eleanor has an ostomy and has been on TPN since 1983 due to radiation enteritis. A retired school nurse teacher, she plays golf, enjoys travel and runs an Oley support group. Eleanor mixes the additives into her TPN so she can travel easier. She has attended several Oley Conferences.</p>
FEB. '04	<p>Linda Gold, RN Brookline, MA (888) 610-3008 EST</p>	<p>Linda is a retired nurse with a diffused motility disorder, Hollow Visceral Myopathy. She is currently on TPN and was on HEN for several years previously. She has a g-tube for drainage which allows her to eat food by mouth. Linda has an amazingly positive attitude. She is widowed with two adopted children.</p>
	<p>Lou Pacilio Leeds, MA (888) 650-3290 EST</p>	<p>Diagnosed with sarcoidosis (swallowing disorder), Lou was on TPN briefly, then weaned to tube feeding 4-1/2 years ago. He has a J-tube and an ostomy, and works part-time as a radiologist. He is experienced with changing feeding tubes caring for ostomy sites, and coping with not being able to swallow his own saliva in public.</p>
MAR. '04	<p>Marie Hartwick Little Rock, AR (888) 610-3008 CST</p>	<p>Marie began TPN in 1982 due to SBS secondary to Crohn's Disease. After 12 years she ran out of access and transitioned to HEN. She has a g-tube and receives Vivonex via a Patrol pump. She's had an ostomy twice, and over 50 surgeries. She is 56 y.o., a single mother and ran a media campaign to get coverage for her HPN.</p>
	<p>Jim Cowan Cleveland Heights, OH (888) 650-3290 EST</p>	<p>A long time consumer, Jim has been on HPN since 1977 due to Crohn's disease. He supports both the Oley Foundation and the Crohn's and Colitis Foundation. Jim has experience with many of the issues surrounding home PN, a great sense of humor and can be a wonderful resource to new and long time consumers.</p>

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