Life Interrupted: Learning to Live with SBS

Leah Atkinson

The dictionary defines *cope* as “to contend with difficulties, especially successfully.” Based on this, we as humans must be in a constant state of coping; we just don’t realize it. We contend with difficulties that vary from minute to seemingly insurmountable.

We seem to begin using our coping mechanisms at birth, as we enter the loud, complex world of the human race. I’m sure this abrupt change is overwhelming to a newborn! Likewise, a catastrophic illness can be overwhelming, to the person affected as well as his or her family. Whether someone is born with medical problems, or they develop later in life, learning to cope with all of the related issues is a vital, ongoing process.

My Sons

I have two sons; both appeared to be perfectly healthy at birth. They were a standard length and weight for newborns. They cried, nursed, slept, and pooped like newborns. They loved to be cuddled and held. And, of course, they were the most beautiful babies ever.

As my older son, Jameson, changed from a baby to a little boy, things continued to progress normally—until he was three years old, when he began to have severe stomachaches. It was shortly after the birth of our second child, Ross, and we initially thought the stomachaches could be psychosomatic, due to the change in family dynamics. After they worsened

Dehydration: Q&A with Dr. Darlene Kelly

The human adult body contains 60 percent and 55 percent water for women and men respectively. The brain and heart contain 73 percent water, the heart 83 percent, and even bone is 31 percent water, according to the U.S. Geological Service Water Science School. Therefore, when fluid balance is upset, the effect can be widespread throughout the body. This is of particular concern to consumers of home parenteral (HPN) and/or enteral nutrition (HEN) and those with short bowel syndrome (SBS).

Q1: Dr. Kelly, what is dehydration? What causes it?  
A1: Dehydration occurs when fluid losses (urine output, diarrhea/high ostomy output, sweat, breath, and other smaller fluid outputs) exceed fluid intake (liquids, water content of food, HPN, and other IV fluids*). It often occurs when there is watery diarrhea or high output from the ostomy, as may happen with diarrheal diseases. In SBS occurring after removal of sections of the small intestine with or without colon, sweets or high salt intakes can also cause excessive

Dehydration Q & A, cont. pg. 10  
In Memory of Mary Patnode

It is with overwhelming sadness that we share the news of Mary Patnode’s death (April 18, 2014). Mary was a delightful woman. It was a pleasure to know and work with her. Her leadership as President of the Oley Foundation Board of Directors was outstanding and we will miss her terribly.

Many of you knew Mary from Oley conferences. She was such a presence! A home parenteral nutrition (HPN) consumer, she often spoke at the conference about her experiences and coping techniques. Whether you met her at lunch or at the registration table, her warm smile, great listening skills, and generous spirit would quickly make you feel at home and comfortable seeking advice.

Mary served on the Oley Foundation Board of Directors for several years, and as president of the Board
Living with SBS, from pg. 1

and continued on a semi-regular basis, my husband, Steve, and I knew there must be a physical problem.

Jameson battled these intermittent stomachaches throughout his young life. At times they were so severe that he would roll around on the floor for hours, crying in pain and saying he felt like he was going to die. None of the prescribed medications provided relief. Despite a number of tests, their cause was never determined. Ironically (in light of future events), their frequency and severity lessened as Jameson got older, until they virtually subsided. Then, out of the blue, when Jameson was sixteen, unbearable abdominal pains sent him to the emergency room (ER) in the middle of the night.

Emergency Surgery

After spending the remainder of the night in the ER, Jameson was admitted to the hospital. They wanted to keep him medicated and determine the cause of his pain. A CT scan revealed he had suffered a mid-gut volvulus and needed emergency surgery. In the meantime, however, Jameson went into shock and was rushed to the intensive care unit. When he was stable enough, he was hurried to the operating room (OR), for what we thought would be a fairly routine intestinal resection. Later we were told Jameson was extremely lucky to have even made it through the surgery alive.

Our handsome, smart, funny teenage son now had three feet of small intestine left, and a condition known as short bowel syndrome. The surgeon explained that Jameson’s situation had been much worse than he had expected; most of the small intestine had been necrotic (dead) due to a lack of blood supply. He then went on to say that Jameson might not make it through the night…the next 24 to 48 hours would be critical…he might not make it through the night…the situation had been much worse than he had expected; most of the small intestine had been necrotic (dead) due to a lack of blood supply. He then went on to say that Jameson might not make it through the night…he might not make it through the night…the next 24 to 48 hours would be critical…he might not make it through the night…

Unfortunately, two weeks later, a third trip to and cope with his new life.

The Early Days

In a matter of hours, our entire family’s world had changed forever. Now the healing process would begin. Seeing him for the first time, with all of the tubes, monitors, IVs, and bandages, only seemed to reinforce my feeling that he would survive this. We spent that first night comforting Jameson and gently explaining what had happened. Although he was on life support and couldn’t speak, he would nod his head in understanding, and then quietly fall back to sleep.

He ended up spending five weeks in the hospital. He underwent two more extensive surgeries and had an IV port placed so he could receive parenteral nutrition (PN). He emerged from the second surgery, which took place just thirty-six hours after the initial one, with a temporary jejunostomy in place. It had been recommended so the remainder of Jameson’s very fragile intestine could heal.

Jameson accepted this new part of his anatomy without reservation. Instead of being repulsed by it, he took great interest in it. Jameson’s very fragile intestine could heal.

During this initial phase of his recovery, he had a very positive attitude, a good sense of humor, and great friends to help him adjust to and cope with his new life.

Unfortunately, two weeks later, a third trip to the OR was required. Jameson had begun running a fever a few days earlier; a CT scan determined there was another section of necrotic small intestine. This surgery resulted in the loss of another foot of intestine, as well as the destruction of our positive attitudes.

Everything went downhill, from Jameson’s strength and pain tolerance, to his mood. I had to force him to ambulate and sit up in a chair. He was constantly nauseated. He was on life support and couldn’t speak, he would nod his head in understanding, and then quietly fall back to sleep. He ended up spending five weeks in the hospital. He underwent two more extensive surgeries and had an IV port placed so he could receive parenteral nutrition (PN). He emerged from the second surgery, which took place just thirty-six hours after the initial one, with a temporary jejunostomy in place. It had been recommended so the remainder of Jameson’s very fragile intestine could heal.

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Everything went downhill, from Jameson’s strength and pain tolerance, to his mood. I had to force him to ambulate and sit up in a chair. He was constantly nauseated. He was weak and plagued with dizziness. He developed insomnia. He didn’t joke around anymore, he became annoyed easily, and he really didn’t even enjoy visitors. I, too, became very down. I either wanted to cry or scream most of the time, but I refused to cry in front of anyone, especially Jameson, and I thought screaming would probably get me escorted out of the
Swallowing Solutions

I am a PEG user (nine years) and cannot swallow. Saliva was a problem, so I have started using a bottle-holder vest for spitting. This vest permits one layer of clothes in hot weather and freedom to wear various non-pocketed clothes. Edwina Sutherland can make these vests or share a pattern. You can contact Edwina through her Web site, www.edwinarichards.ca, or at 613-730-4265 (Ontario, Canada).

—Rob Frayne
robnfayne@gmail.com

We shared Rob’s suggestion with enteral nutrition consumer Rick Davis, who replied with the following additional suggestions:

I once had someone introduce me to a not-Oley, not-clinical audience by saying: "Every minute or so, we unconsciously swallow our saliva. It is a natural thing we do without realizing it. It is part of our digestive process and saliva helps our dental health. Rick cannot swallow. To understand Rick better, make a conscious effort to NOT swallow your saliva while he is speaking—which will only be about fifteen or twenty minutes."

When I first lost the ability to swallow and began using a feeding tube, I had to spit every few minutes. After eighteen months of that, I was sitting in a meeting at an Oley conference, spitting into a coffee cup. A gastroenterologist who was sitting beside me (Dr. Mark DeLegge) turned to me and asked, “Have you tried glycopyrrolate?” He said it might reduce my saliva. I wrote it down and my primary care doctor prescribed it.

After experimenting to find the right dosage (starting with half a tablet), I learned that two 0.2 mg tablets per day reduce my saliva enough that I need to spit only once or twice an hour, but do not reduce it enough to make my mouth dry (some saliva in the mouth helps dental health). I have been using glycopyrrolate for almost twelve years with no apparent negative side effects.

Because I have reduced the amount of saliva I produce, I can spit discretely into a small bottle and I only need to empty and rinse it every couple of hours. Any drinking fountain or faucet will do for rinsing. I order Nalgene bottles of all sizes from REI online—small ones for spit cups and larger ones for dissolved medications. Usually, I am holding a small bottle. Most people wouldn’t notice it unless they were looking for it. When I’m not holding it, it fits easily into a shirt or pants pocket.

We all find different solutions to situations unique to our condition. Yours may be the best for you. Mine is the best for me. Thanks for sharing your solution.

—Rick Davis
rickdavis320@comcast.net

The different sized bottles Rick uses. Most people would not notice the small cup in Rick’s hand unless they were looking for it. When he’s not holding it, he slips it into his shirt or pants pocket.
Enteral Connector Changes: FAQs for Blenderized Diet and Other Patient/Caregiver Concerns

Tom Hancock, GEDSA

The Oley Foundation received a good deal of mail in response to the article in the January/February newsletter called “New Connectors for Enteral Feeding Tubes.” The article outlined changes that are being implemented to reduce the possibility of tubing misconnections.

Tom Hancock, who wrote that article, has addressed some of those questions for us. If you have additional concerns or questions, please send them our way and we will share them with Tom. GEDSA representatives will also be available to answer questions at the Oley Annual Conference in Orlando in June. Be sure to stop at their exhibit booth or attend the Tube Feeding Workshop for the latest information and to get your questions answered. For a copy of the first article, which explains the changes in detail and outlines the timeframe for the changes, go to www.oley.org or call (800) 776-6539. Details also available at stayconnected2014.org.

Will low-profile (skin-level) gastrostomy tubes (G-tubes) be changed?

Connectors on low-profile feeding tubes are out of scope of the new design standards and will not be changed. Extension sets used with low-profile G-tubes will have the current connector on the end that is inserted into the G-tube, and the new ENFit connector on the end that connects to administration sets and syringes.

Why does this new system require that the old system become obsolete?

The goal of establishing an EN connector design standard is to improve patient safety by reducing the risk of a tubing misconnection, which is rare but dangerous and can even be fatal. The most effective way to reduce the risk of misconnections is to ensure that connectors of different delivery systems (i.e., EN and IV) are not compatible. Also, patients today are typically quite mobile, moving between hospital, post-acute facilities, and home. If each setting used feeding devices with either old or new connectors, there is a strong likelihood of disruption of therapy due to incompatibility, as well as potential for a misconnection.

Will the new connectors allow for venting?

Yes, venting will work in the same manner it does currently. Note that venting a feeding tube that has an ENFit connector will require a syringe that has an ENFit connector.

Will it be possible to hydrate with a catheter-tip or oral-tip syringe?

To hydrate through a feeding tube that has an ENFit connector, you will need a syringe that has an ENFit connector. Catheter-tip and oral-tip syringes will not fit ENFit connectors. The ENFit connector was designed specifically to prevent the use of catheter-tip syringes in order to reduce the risks associated with misconnection among medical delivery systems. Syringes with the ENFit connector will be available in advance of feeding tubes with the ENFit connector.

Will thicker formulas and blenderized foods pass through the new ENFit connector?

The new EN feeding design standards were developed with current practice in mind and specific requirements to avoid any disruption of therapy. The bore size (or hole) in the ENFit connector was designed to be consistent with the bore size of the current connector, and feeding through devices with these connectors is intended to be consistent with current practice. For more information, contact the manufacturer of the EN device in question directly.

Will there be adapters? Will they fit different kinds of syringes?

During the transition period, a transition connector that will be compatible with the new EN-specific syringe will be available. The adapter (or transition connector) will make the new syringes compatible with current feeding tubes. After the transition period, you will not need an adapter to fit an ENFit syringe to an ENFit feeding tube. As noted above, catheter-tip or oral-tip syringes will not work with the new ENFit connector feeding tube. [Editor’s note: Sometimes catheters that are not designed for EN are placed as feeding tubes (for example, a Foley catheter). GEDSA advises against and cannot address any off-label use.]

Will using a transition connector on a bolus extension set make the hole in the bolus extension–syringe connection smaller?

Yes, the hole on the transition connector will likely be smaller than that in the catheter-tip syringes currently in use, but it won’t be smaller than the end of the extension set that connects to a low-profile device. As long as the end of the extension set remains the smallest hole in the system, the flow rate properties are not expected to change from the current configuration.
Will bolus syringes used for feeding blenderized diets be available with the ENFit connections? Will the hole at the tip of the syringe be smaller, and will this impact the ability to feed?

All syringes intended for use with EN feeding tubes in the future will require the new ENFit connector. EN-specific syringes with the ENFit connector will likely have a smaller hole than the catheter-tip syringes currently in use. However, the hole will not likely be smaller than the opening on the patient access end of the (bolus) extension set on most low-profile devices. As long as the end of the extension set remains the smallest hole in the system, the flow rate properties are not expected to change from the current configuration. For other devices (i.e., non–low-profile), the industry is currently evaluating the impact of a smaller size of the hole.

Will there be color-coded EN syringes available to manage medication administration?

There are no color-coding requirements in the standards. Syringe manufacturers may offer EN-specific syringes in one or more colors.

Will pharmacies stock EN syringes?

Distributors and pharmacies will be alerted of this potential need, but ultimately it is up to the pharmacy to decide to carry these items. Check with your local pharmacy, home medical equipment supplier, or home care company about the availability of EN-specific syringes.

Once syringes are EN-specific, will there be greater insurance coverage?

GEDSA and its manufacturer and supplier members are not in a position to address issues related to insurance coverage or reimbursement. Check with your insurance provider for their specific policy.

What about non-traditional use of EN patient access devices?

GEDSA advises against and cannot comment on or address any off-label use.

GEDSA note: All products and product designs are the responsibility of each manufacturer, distributor, or supplier. Products with the ENFit design features may be pending regulatory clearance or may not be available in certain areas. Consult your supplier representative for product-specific use, availability, indications, contraindications, precautions, and warnings. This material is intended for informational purposes only and should not be used to replace regulatory or company-specific documents, nor should it replace the advice of a qualified professional.

Timeline for New Connectors (US, Canada, Puerto Rico)

<table>
<thead>
<tr>
<th>Timeframe</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>4th quarter 2014</td>
<td>Feeding/administration sets with ENFit connectors available</td>
</tr>
<tr>
<td>1st quarter 2015</td>
<td>Syringes with ENFit connectors available</td>
</tr>
<tr>
<td>2nd quarter 2015</td>
<td>Feeding tubes with ENFit connectors available</td>
</tr>
<tr>
<td>January 2016</td>
<td>Transition complete</td>
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Mary Patnode, from pg. 1

since 2011. She volunteered with HPEN consumers long before that. Mary started on HPN in 1980 due to Crohn’s disease and short bowel syndrome, and within a few years was active in a support group in Minneapolis, where she lived. She joined the Lifeline Foundation, and then the Oley Foundation when the two organizations merged into one. She was an Oley Ambassador from 1986 to 2014. Think of the hundreds (maybe even thousands?) of lives she must have influenced.

In an article in the Journal of the Association for Vascular Access in 2012, Mary wrote, “Survivor,’ ‘lifer,’ ‘long-termer,’ ‘patient,’ ‘consumer,’ and ‘HPNer’ are all labels I could wear. After 32 years of receiving HPN, it is difficult to distinguish where the catheter ends and I begin.…Following 15 years of struggling with malnutrition and repeated surgeries,… HPN promised the benefits of consistent energy, although intrusive and carrying its own risks…. I kept my daily ‘date’ with ‘Hyper-Al’ faithfully and was able to pursue a career, finish an advanced degree, work full time, buy a home, participate socially, get married, and enjoy a family that came to me complete with children and grandchildren. I still ‘connect’ every day and I do make compromises, but they fade in light of the benefits of having regular, adequate nutrition.”

She continued, “I’m lucky to have had consistent access to the best resource team available, and I find I learn so much from others receiving HPN. The Oley Foundation…has introduced me to a wealth of survivor stories—individuals who rise to meet challenges and face what could be debilitating circumstances. I especially respect the informed and articulate young people who exercise their independence to explore the world with an adventuresome spirit while living with HPN. They are asking questions I didn’t even consider. They encourage others with their presence, enthusiasm, and high expectations.”

Mary, too, encouraged others with her “presence, enthusiasm, and high expectations.” She was an exceptional woman, and she will be missed greatly. ¶ If you’d like to share any of your memories about Mary, we’d be happy to share them with her family. E-mail Cathy at harrinc@mail.amc.edu.

Pediatric Intestinal Failure Symposium

September 11–13, Atlanta, Georgia
Sponsored by Children’s Healthcare of Atlanta and Children’s Hospital of Pittsburgh of UPMC
Identifying, Planning, and Driving High Quality Outcomes During the Pediatric Intestinal Failure Journey

The symposium will focus on new discoveries and developments concerning the etiology, pathophysiology, surgical and nonsurgical therapies, and outcomes-based research for intestinal failure in children. Focus areas will include the latest in medical therapies for intestinal failure, improving outcomes through multidisciplinary intestinal rehabilitation programs, and the latest in pediatric intestinal transplantation.

Visit www.pedsintestine2014.com for registration information and a copy of the full agenda.
Team Inspire

I’m making friends here on Inspire:
The kind of friends who don’t require
that I smile and be at my best,
Who don’t consider me a pest
when I’m down or need to vent,
Who’ve words of support so gladly sent.
These are people I’ve never met;
They’re only names to me and yet
I feel a closeness to them all
And I never fail to heed their call
when they reach out, too sick to cope
with their lives, and I send them hope
in the form of words and offered prayers.
Here there’s no need to put on airs
and pretend to be stronger than we are.
This is our community and we come from afar
to offer support, encouragement, advice;
Opportunity each day to do something nice.
If I can share in another’s pain,
I find that I’m the one to gain.
So here’s to those who run this site!
I thank you, with all my might.

— Candace E. Barnes

Candace is a regular participant on Oley’s Inspire chat forum. Here
she shares her thoughts about what this program means to her.
For more information or to join, go to www.oley.org/forum.htm.

Center of Experience

This column is meant to highlight institutions that specialize in caring
for HPN and HEN consumers. Oley does not endorse any center but
brings this to our readers strictly as an informational tool. For a listing
of other experienced centers visit www.oley.org or call (800) 776-OLEY.

Henry Ford Hospital, Intestine and Multivisceral Transplant
Program, Detroit, Michigan

The Henry Ford Hospital Intestine and Multivisceral Transplant
Program, established in 2010, is the first and, at this time, only
program in Michigan performing intestine transplantation. Their
intestine transplant team approach offers patients care from pre-
transplantation through recovery and rehabilitation. Intestinal
transplant program patients receive service provided by specialists
in gastroenterology, intestinal transplant surgery, nutrition, social
work, psychology, and rehabilitation.

Each patient is also assigned an intestinal transplant program
coordinator—a nurse who coordinates all aspects of care and serves as
the patient’s liaison throughout the transplant process. The transplant
coordinator provides educational materials and support to patients
and families and is available twenty-four hours a day to respond to
medical emergencies.

For more information, call Nemie Beltran, RN, at (313) 916-1826
or visit www.henryford.com/transplant.
Inspire Community

The Oley Foundation teamed up with Inspire in 2008 to create an online community where home nutrition support consumers, their friends and family can find and support one another, share stories, and build a network of online friends. Now the Oley Inspire forum has more than 4000 members! How and why do people join the forum? These members say it all:

“I found this site by accident while searching online looking for solutions to irritated skin due to leakage and tube clogs. I love this site and feel blessed to have been accepted as a member of an outstanding community within INSPIRE’s great network of support groups. I was desperate and grasping at straws to find ANY help for [my brother-in-law] after Drs gave up on him and figured he would die soon.” —Duvie (member since 2013)

“I think that what Oley has done with developing this support site is phenomenal, and only wish that I had discovered it earlier. The accumulated experiences of the members here enable us to give each other advice, support, and encouragement, and it is nice to know that [Oley and Inspire staff are] keeping an eye on the site and taking down offensive posts.

“The site has become an integral part of my day. Being able to help others by sharing my experiences has helped me to see that my experiences can be turned to good use, thus making sense of what might otherwise seem senseless. Inspire is a part of my life now, and when I am unable to post and follow the discussions because of illness or hospitalization, I miss Inspire tremendously. It is indeed inspiring to see people helping one another through this journey of ours. Sharing with others gives a meaning to my everyday life.” —Candacepoet (member since 2009)

Membership in the Oley forum is different than membership in the Oley Foundation itself. We encourage our Oley members to also join the forum, and our forum members to also join the foundation and experience some of Oley's other programs. To join the forum, go to www.oley.org/forum.htm.

Be Part of Oley History

30th Anniversary T-shirts Now 50% Off!

- Wicking fabric golf shirts, $22 now $11
- Cotton golf shirts, $16 now $8
- T-shirts, adult $13 now $6.50
- T-shirts, youth $10 now $5
- Sweatshirts, $22 now $11

Shipping: $2.95 single shirt, or $5 for two

Order at www.oley.org or call for sizes and colors available.

Bolstering the Community that Supports Us

We at Oley are so grateful for the generous outpouring of support for our community. Your gifts allow Oley to focus on providing critical medical information and coordinating peer connections, rather than continually having to ask for more funding.

We are inspired by members like Dale and Martha Delano who not only give generously throughout the year, but also maximize their donation by accessing a matching gift program from Dale's former employer, and are members of Oley's Horizon Society. We recently asked Dale and Martha what motivates their actions. Their response:

“We have strong reasons for our financial commitment to Oley. We want to support a community for those who have conditions like Dale's so they can benefit from each other's experiences, and we want medical professionals to work cooperatively to help address our challenges. We feel that Oley does both of these things remarkably efficiently and effectively, as well as disseminating information via conferences, the Internet, and publications.

“Further, we find it tremendously empowering to get support from and share experiences with others who have similar medical issues. For all of these reasons we want Oley to continue to thrive.

“There are many good causes out there that one's donations can support, and we all make our choices, but Oley definitely earns ours.”

In this spirit, we ask you to join us in building a firm financial foundation for Oley. You are invited to make a donation online at www.oley.org, or in the envelope included in this newsletter. Many thanks for your support!

Dale developed Crohn's disease as a young man, has had several intestinal surgeries, has an ileostomy, and has been on home parenteral nutrition (HPN) every night for over twenty-one years. Even so, he says his health is remarkable, "thanks to caring and skilled doctors, supportive suppliers, my caring and committed wife, Martha, and the Oley Foundation." He and Martha have been blessed with three children and five grandchildren who have enriched their lives.
Nutrition and You
Proton Pump Inhibitors: Are They Inhibiting More than Acid?

Proton pump inhibitors (PPIs) work by blocking the production of acid from the cells in your stomach. Your clinician may recommend the addition of a PPI to your home parenteral or enteral nutrition (HPEN) regimen if needed to reduce the amount of acid produced. Histamine H2-receptor blockers are another type of acid-reducing medications, but these work on different cells to reduce the effect of excess acid production. PPIs appear to be more effective and safer than H2 blockers and have become the preferred medication for reducing the amount of acid in the stomach. In some cases, a prescriber may use both PPIs and histamine H2-receptor blockers in a nutrition support patient.

Since some PPIs are now available over-the-counter, long-term (or even lifetime) use is common. Often this occurs without medical supervision or an appropriate indication (“as seen on TV” is not an appropriate indication!). Although these drugs are safe, new data has shown that long-term acid suppression from PPIs may reduce the absorption of important vitamins and nutrients. Recently, the U.S. Food and Drug Administration (FDA) revised the product labeling for PPIs to describe the possible increased risk of fractures with high-dose and long-term use. Since nutrition support consumers may already be at risk for nutritional deficiencies, fractures, and infections, the risk-to-benefit balance of using PPIs must be carefully evaluated on an individual basis.

PPIs and Nutrition Support

Acid is required for normal digestion. In patients receiving HPEN or those that secrete excessive amounts of gastric acid, PPIs are used to reduce the acidity and volume of gastric fluid produced. Knowing there are some potential risks associated with long-term use of PPIs and being familiar with early signs of complications, nutrition support teams and patients can work together to eliminate or reduce the risk of adverse outcomes.

Fractures and Calcium

Many studies have concluded that PPIs are capable of affecting calcium absorption. Although short-term therapy was tolerated, long-term PPI therapy was associated with increased bone fractures, especially the hip. A history of smoking further increased the risk of PPI-associated fractures. The risks and benefits for continuing long-term PPI therapy should be assessed. If oral calcium supplementation is recommended, the soluble citrate salt form is preferred rather than the carbonate form since it is ready to absorb without acid.

Vitamin B12

B12 is in the multivitamin infusion that most HPN patients receive and in most oral multivitamins. Deficiencies in vitamin B12 have been noted in patients receiving PPIs even if supplemented with the recommended dietary allowance of 7 to 50 mcg/day. Vitamin B12 is bound to other nutrients; it needs the acidity of gastric juice in order to be released and absorbed. Since PPIs decrease gastric acidity, B12 deficiency can occur.

Symptoms of deficiency may include loss of concentration, fatigue, and lightheadedness. Chronic vitamin B12 deficiency can lead to neurologic disorders, depression, and dementia, which can be reversible if diagnosed in a timely manner. In addition, vitamin B12 is crucial for bone formation. Even without symptoms, vitamin B12 serum levels should be checked after three to four years of chronic PPI use.

Magnesium

PPIs may affect the absorption of magnesium from the GI tract if used long-term. Providers should monitor for unexplained manifestations of magnesium and potassium deficiencies in long-term PPI users. Of note, when magnesium levels remain low, potassium levels will also drop. Fortunately, the low magnesium levels appear to be reversible upon stopping PPIs.

Infections

An increased risk of GI infection has been associated with decreased gastric acid levels. When gastric acid is blocked or significantly reduced, as occurs with PPI use, the body is not able to kill certain bacteria or parasites, therefore increasing the potential for GI infections from sensitive organisms such as salmonella, C. difficile, and giardia. It is important for patients to immediately notify their health care provider if they experience unexplained and persistent vomiting and/or diarrhea, bloody stools, fevers, or pain.

Factors to Consider

With the widespread use of PPIs, the safety of long-term use needs to be considered and monitoring is key to ensuring the best possible outcome for every patient. For the nutrition support team to determine if long-term PPI use is beneficial, they should regularly evaluate the patient to assure:

1. The indication for the PPI is appropriate and still relevant;
2. Long-term acid suppression continues to be necessary (perhaps the patient has decreased HPN or is eating regular meals as well);
3. Signs and symptoms of vitamin B12, calcium, and magnesium deficiencies are monitored.

Additionally, patients should report any new signs or symptoms of the deficiencies discussed above, as well as any new medication (over-the-counter or prescribed) or supplement to their nutrition support specialist and primary care physician.

Conclusion

As with any medication, there are benefits and risks. With careful monitoring by the nutrition support team, PPI use can be a successful component of HPEN management.

Written by Negin Moon, Mercer University College of Pharmacy, Doctor of Pharmacy Candidate, 2014; Kevin M. McNamara, PharmD, CNSC; and Brenda L. Gray, PharmD, CNSC, BCNS, BioScrip Infusion. Reviewed by Carol Ireton-Jones, PhD, RDN, CNSC, and Laura Matarese, PhD, RD, CNSC. References available upon request.
Dehydration: Research Supports Treatment at Home
Denise Konrad, RD, LD, CNSC, and Mandy Corrigan, MPH, RD, LD, CNSC, FAND

Denise and Mandy were awarded Oley’s HomePN Research Prize, sponsored by Nutrishare, Inc., in 2013, for their research on dehydration. Their research, undertaken in conjunction with Cindy Hamilton MS, RD, LD, Ezra Steiger, MD, FACS, FASPEN, and Donald F. Kirby, MD, CNSC, of the Cleveland Clinic, Cleveland, Ohio, is summarized here.

At Cleveland Clinic, additional bags of intravenous fluids (HIVF) were provided to home parenteral nutrition (HPN) and HIVF patients who were at high-risk of developing dehydration. These HIVFs were ordered by the HPN physician for immediate use in the home when the patient displayed the signs and symptoms of dehydration. High-risk patients were defined as those with high-output ostomies, fistulas, and/or drains. These patients were taught how to identify dehydration before they were discharged, and were advised to contact the hospital's home nutrition support service as soon as these symptoms developed and before using the additional HIVFs. The goal was to help them avoid emergency room (ER) treatment or hospital admissions.

We defined dehydration as having greater fluid losses (urine, stool, vomiting, drain output) than fluid intake (oral liquids, enteral nutrition, HPN, HIVF) based on the patient’s intake and output (I/O) records, with at least one physical symptom and/or alteration in labs compared to the patient’s baseline. Standard treatment of dehydration was 1 liter HIVF daily for 3 days, plus prescribed infusions. We considered their dehydration resolved when the labs were back to normal, or they no longer had the physical symptoms.

The Numbers
We looked at the records of 308 home nutrition support patients (both HPN and HIVF) managed during 2010. We found the most common diagnoses were Crohn’s disease and cancer with malabsorption, fistula, or obstruction. Most patients had an ostomy. Following hospital protocol in identifying high-risk patients, HIVFs were ordered in 161 of the 308 patients.

Among these 161 patients, over half required additional HIVFs due to at least one episode of dehydration. Many patients had multiple episodes, with a total of 201 episodes reported. We noticed that for every 5 year increase in age, the odds of having more than one dehydration episode increased 20 percent. Older patients, those with increased ostomy output, and/or those with negative I/O data were more likely to have more than one episode of dehydration. Eighty percent of the time, I/O data was consistent with the signs and symptoms of dehydration.

More than three-quarters (84.5%) of the 201 episodes of dehydration were successfully treated at home with additional HIVFs. There were only 9 ER admissions (4.5%) and 22 hospital admissions for dehydration (11%). One patient, who was non-compliant, had 4 admissions.

Conclusions
Dehydration is common in HPN/HIVF patients, especially those with malabsorption and an ostomy. A protocol to identify HPN/HIVF patients at risk of dehydration with provision of additional HIVF on-hand in the home can reduce ER treatment or hospitalization. This is easier on the patient, and could potentially save health care costs.
Dehydration Q & A, from pg. 1

Ingested fluid loss. Other causes of dehydration include fever, vomiting, and medications (especially diuretics).

I often have described what would happen if someone were in the desert without a water supply. The kidneys try to hang on to fluid by decreasing urine output. The urine becomes concentrated (dark amber to brown) and the volume is decreased. Typically thirst is prominent and the individual would drink water when it is available. In the case of SBS, the water might actually be counterproductive (explained below).

The flip side of dehydration is overhydration. Normally when fluid intake exceeds output, the kidney compensates by increasing urine volume. The analogy here is when people drink excessive amounts of fluid (beer?), they may find themselves in the restroom repeatedly to pass urine. However, in kidney insufficiency, this compensation may not be possible and excess fluid is not excreted. In that case, the person gains weight quickly. This can be of particular concern in either kidney or heart failure and is a reason to see a clinician immediately.

Q2: Why is dehydration a problem (short-term and long-term effects)?
A2: The short-term effects are decreased urine output, weight loss, fatigue, increased thirst…often leading you to drink fluids, usually water. And, as noted above, drinking excessive “free” water can be counterproductive.

If dehydration is not evaluated and reversed, it can lead to much bigger problems. Chronic dehydration can lead to kidney stones, as well as kidney failure and the need for dialysis, sometimes followed by kidney transplant. Therefore it is preferable to avoid dehydration!

Q3: Are some people more susceptible to dehydration than others? Are there activities, conditions, or situations that make us more vulnerable?
A3: Dehydration is one of the serious complications of SBS. This is usually because of increased intestinal fluid outputs with SBS.

When someone with SBS, especially in the absence of colon, eats a diet with high sugar and/or salt content (aka high osmolality intake), the concentration of the sugar and/or salt components pulls water from the bloodstream and cells in order to dilute the concentration within the shortened bowel. The same thing occurs in people with an intact small intestine and colon, but the intact colon has the ability to absorb water greatly in excess of the usual requirement, returning it into your system. Unfortunately the shortened bowel in absence of colon cannot reabsorb the fluids from the small intestine, and the fluids are flushed out of the system.

Activities in very hot weather cause fluid losses through sweat. This is why athletes are very careful to take in appropriate fluids when they anticipate exercise as well as during the exercise. Any diarrheal disease can cause dehydration, as can some kidney diseases that abnormally increase urine output.

Q4: Can I anticipate when dehydration may be a problem? What are the symptoms of dehydration?
A4: When diarrhea is worsened and fluid is not replaced either orally or intravenously, dehydration is common. In very hot weather fluid losses are also prominent. Rapid weight loss could be a sign that you are dehydrated. Since the first thing that happens is the kidneys decrease output, close attention to urine color is also important. A change in color from light yellow to dark amber and brown is a good clue that dehydration is developing, although dehydration is not the only possible cause for such a change.

At that point, it is quite useful to measure the urine volume for twenty-four hours. The urine output that we aim for in our HPN practice is at least one quart daily. These findings (the rapid weight loss, decreased urine output, and dark urine) usually precede any changes measured in laboratory tests (particularly blood urea nitrogen [BUN] and creatinine).

Other symptoms and signs can include light-headedness, especially when you rise from a lying position; rapid pulse; excessive thirst; sunken eyes; dry mouth and eyes; fatigue; lethargy; and “tenting” of the skin. “Tenting” refers to lifting a bit of skin on the back of the hand; when it makes a tent-like shape that stays for several seconds, it indicates that the tissue is dry (dehydrated). While most of these signs and symptoms are non-specific (meaning that taken alone, none of them point specifically to dehydration), several of them occurring together in a person who is at risk may indicate dehydration.

Q5: I’ve been told I shouldn’t drink plain water. Why is that?
A5: Plain water or “free water” has an extremely low osmolality, approaching zero, because it contains virtually no salts (sodium, potassium, chloride) or other components. By contrast, the fluid in the body contains high amounts of sodium and has an osmolality of about 300 mosmols. The body tries to maintain an equal distribution of sodium across membranes. Thus if sodium levels are high on one side of a membrane and nearly zero on the other side, the sodium will move across the membrane to where there is less sodium. Where sodium goes, water follows. Putting this into the context of the body, ingested water in the intestine will cause sodium from the blood side (high concentration) to move into the intestine, pulling water with it, which equals DIARRHEA! So in the case of SBS, water is a very poor hydrator because it causes loss of fluid (in diarrhea) greater than the amount of fluid (water) consumed. What you can do instead is drink oral rehydration solution!
Dehydration and Running

Emma Tillman

I did a lot of brainstorming with my pharmacists and nurses at my home infusion company to come up with a plan that will allow me to train for, and run, marathons.

Here’s our plan to keep me hydrated:

- If I run in the morning, I stop my nightly parenteral nutrition (HPN), then run—no pre-run hydration. If I run in the late afternoon or evening and I feel somewhat dry before starting, I sometimes infuse IV fluid (IVF) pre-run. This is more important if I will be doing a long run or be out longer than 2 hours or if it is really hot.

- I usually weigh myself pre- and post-run, calculate my sweat rate, and then replace fluid based on weight loss. I keep a spreadsheet of sweat rate, miles run that day, and the temperature outside. This helps me estimate losses and needs based on temperature and distance.

- For runs greater than 2 hours, I infuse IVF in an eclipse ball while running. The eclipse ball infuses a set amount of fluid in a set amount of time. I use a 500 ml ball that infuses over 2 hours. The advantage is that I do not need a pump and I do not need to worry about gravity. The ball pushes the fluid at a given rate. They have been used for home antibiotic infusions and work well for short and relatively small volume infusions. If my weight is still lower than my pre-run weight, I will often infuse hydration solution post-run.

- I have HPN 6 nights/week, so I typically schedule my day off HPN around a rest or easy workout day. I always do HPN the night before and after a long or hard workout.

Emma Tillman is a long-distance runner, a pharmacist, and an HPN consumer (due to gastroparesis).

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hospital. I felt so bad for my son, that everything that had happened to him was just unfair.

Very slowly, we both began to climb out of our respective pits. I continued to feel sorry for myself, but I knew I needed to focus my energies on Jameson and really encourage him. Steve and I both believed if we could just get Jameson home, everything would be better.

**Back Home**

When he was finally discharged, Jameson was relieved to be home. We were so happy to have our family all under one roof again, but I must admit, having Jameson home was both wonderful and terrifying. At home, there were no nurses to bring him pain or nausea medicine, administer his home parenteral nutrition (HPN), take care of his ostomy, or monitor him for infections. It was all so overwhelming, such unknown territory for us as parents. Even with a nursing background, I felt totally inept at caring for my own son, physically or emotionally.

In addition to taking care of Jameson, Steve and I realized we needed to keep Ross's life as normal as possible. As I emphasized earlier, Jameson's illness severely changed our entire family. We knew we would have to work extra hard to balance our relationships with each other. I'm sure Ross understood why Jameson required so much of our time, but as a young teen, he had to be jealous of all the attention Jameson was getting. He'd been very good about visiting while Jameson was in the hospital. With school out for summer vacation, we tried to keep him busy with friends and doing activities he enjoyed.

Meanwhile, we worked on strengthening Jameson's physical stamina and his self-esteem. He had lost a lot of weight and muscle mass while in the hospital, and had developed a negative self-image. He began exercising and lifting weights with a personal trainer who had experience with medically compromised individuals. Jameson found it difficult in the beginning, but before long his strength and stamina began to improve. Thanks to his HPN regimen, he also started gaining weight. As he improved physically, it was easier to encourage him to re-enter the social scene. Steve and I chauffeured him to a couple of gatherings, but once he regained the courage to begin driving again, he was on his way back to his old self.

About two and a half months after he came home, Jameson returned to the hospital to have his ostomy reversed and his small intestine reconnected. The surgery went very well, although he had about six more inches of intestine removed due to severe ulceration. Now he was left with only eighteen inches. And, wow, did those eighteen inches usher waste out of his digestive system FAST. Talk about coping! It seemed like the poor kid was running to the bathroom every thirty minutes. He was exhausted, and I was worn out just watching him go back and forth.

Fortunately, the recovery from this fourth surgery went more smoothly than from the previous ones, and gradually Jameson made fewer trips to the bathroom. He returned to school two months into his senior year and fell into a semi-modified routine. He attended a few football games, he went to school dances, he showed up at parties, he remained on the swim team and participated in each meet, he went with friends to Florida during spring break week, and he graduated with honors from high school. To his friends, no matter how his life had changed, he was always the same old Jameson.

**The Latter Days**

Jameson received a scholarship to a college in Florida, eight hours away from our home in Georgia. He was determined to go. It was difficult, at first, to let him, but Steve and I knew it was something he felt he needed to do. During his freshman year, with the assistance of two wonderful campus nurses, Jameson accomplished what he had set out to do—he demonstrated he could take care of himself.

Since that period in 2003, Jameson basically has been taking care of himself. The majority of his adult life has been spent many miles away from us. Sometimes he lived away because of job circumstances; other times it was a matter of choice.

I would like to say he has always taken very good care of himself, but that's not always been the case. During his college years, the stress of being totally responsible for every aspect of his life, from cooking and cleaning, could become overwhelming and detract from his health. Jameson was in and out of the hospital on several occasions with varying complications. He always rebounded, but sometimes it took longer than others. He graduated from the University of Georgia in a timely manner, and then went on to earn a master's degree.

There seems to be a correlation between Jameson's maturity and the state of his health: the older he's become, the more stable his health seems to be. I also feel that the Oley Foundation has been a contributing factor in this scenario. When Jameson was finally able to attend his first Oley conference, he was mesmerized by it. Just being with such a caring, nurturing group of people seemed to give him a new perspective on life, as well as a desire to reach out to other teens and young adults struggling with similar issues.

Jameson has been through some difficult times during his thirteen years on HPN, but he chooses to strive for a positive attitude and enjoy life. If there's something he wants to do, he figures out a way to do it. He is a certified scuba diver, has gone sky diving with his dad, likes swimming and kayaking, enjoys traveling and outdoor concert festivals, and loves going on cruises with friends.

Most recently, Jameson was offered a career change within the insurance company that employs him. He excitedly accepted the position at caring for my own son, physically or emotionally.
Children’s Medicaid Waivers: A New Online Resource

Susan Agrawal

*Complex Child E-Magazine*, a parent-written online magazine for families dealing with medical complexity, has created a new resource to help families obtain Medicaid waiver coverage for their children. A new Web site, www.KidsWaivers.org, will provide information on Medicaid waivers, including a comprehensive list of waiver programs available for children in each state.

**Waivers**

Children who live at home but whose disability or medical condition would require them to otherwise live in an institution (including a hospital, nursing facility, or intermediate care facility) are eligible for Medicaid waivers. Most children on home parenteral nutrition (HPN), and some on home enteral nutrition (HEN), will qualify.

Children who receive HPN or HEN often have huge medical expenses and unmet needs. Even if they have insurance, their policies may not cover critical needs, such as HEN formula or private duty nursing. Medicaid waivers help provide children with more comprehensive coverage, including full primary or secondary Medicaid coverage, and in some cases, additional “Waiver Services” that vary by program. Most of these programs waive family income limits, allowing children of all incomes to access Medicaid.

Each state is allowed to create its own programs for children, typically following four different pathways, including 1915(c) Home and Community Based Waivers; TEFRA/Katie Beckett Waivers; 1115 Demonstration Waivers; and state-based programs. The eligibility requirements and benefits of each program vary considerably from state to state. Because each program is unique, it can be challenging to find information on many of them. We hope to simplify the process by compiling as much information about each program as possible onto one site.

**KidsWaivers.org**

We’ve completed Phase I of three intended phases for the site: creating a comprehensive list of programs in each state, including their target population, level of care, and number of spots. We’ve obtained this information from state and federal government Web sites. Phase II will involve creating individual pages for each state, with families and advocates providing inside information on each program. Phase III will include an advocacy component, connecting families to help preserve these critical programs.

To learn more, visit www.KidsWaivers.org. If you have corrections or additional information to add to the resource, please use the contact form on the Web site or e-mail info@kidswaivers.org.

“Medicaid Waiver programs help provide services to people who would otherwise be in a... nursing home or hospital to receive long-term care in the community.”

— www.en.wikipedia.org
Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributors who help keep Oley programs free of charge to home parenteral and enteral consumers. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

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Abbott Nutrition
Abbott Nutrition is one of the world’s leading authorities in science-based nutrition for all stages of life. Its portfolio of products includes Jevity, Vital, PediaSure Peptide and EleCare, to help patients grow and achieve greater well-being. Visit www.AbbottNutrition.com to find information and education materials to help increase tube feeding knowledge.

Nestlé Health Science
Nestlé Health Science strives to make a positive difference to the nutritional health, well-being, and quality of life of patients through the development and delivery of innovative, medically recognized branded nutritional solutions for acute and chronic conditions.

AMT (Applied Medical Technology, Inc.)
Applied Medical Technology, Inc. (AMT) helped develop the PEG tube, and its founder co-invented the first low-profile feeding device. AMT continues to make innovative medical devices, including the AMT Bridle Nasal Tube Retaining System, the AMT MiniONE low-profile buttons, and the new AMT G-JET low-profile G-J enteral tube.

Dehydration Q & A, from pg. 10

Q6: What is an oral rehydration solution (ORS)?
A6: ORS is a mixture of electrolytes (sodium, potassium, chloride, bicarbonate), carbohydrate (sugar or starch), water, and flavoring that is used to rehydrate people. It is sometimes an alternative to huge IV fluid replacement.

The components of ORS have to be in very specific ratios and in appropriate quantities to be effective. ORS was first used in cholera, the most severe and lethal diarrheal disease in the world. It occurs in large epidemics primarily in Third World countries, where it is particularly difficult to replace sufficient fluids intravenously and safely. The use of ORS in cholera has been called the most important medical discovery of the twentieth century. It has saved millions of lives. Much of this research was done in Bangladesh.

The World Health Organization (WHO) has been particularly involved in the development of ORS formulas. Over the years WHO has designed at least three mixtures for differing conditions that are being used extensively. There are also several commercially produced products available in the U.S. In addition, there are recipes that can be made at home from common food products, usually quite inexpensively. Oley has several ORS recipes available, including a WHO recipe (go to www.oley.org/lifeline/ORS.html or request a copy at 800-776-6539).

Q7: How about caffeinated drinks, such as tea, coffee, sodas, or energy drinks? Are sports drinks good for me?
A7: Tea and coffee are not only a version of “free water” (thus pulling sodium and water from the body into the intestine, equaling diarrhea), but they are also diuretics. Thus they are poor hydrators. Sodas, if sweetened with sugar, have an extremely high osmolality (the result of the sugar), so water is pulled into the intestine, resulting in diarrhea. In the case of diet beverages, they too are equivalent to “free water,” causing diarrhea. Energy drinks for the most part are high osmolality so are not a good choice for those with SBS. Some sports drinks are better than others for improving hydration. However, overall, they are not optimal. The osmolality is too low to be as effective as the best ORS formulas.

Q8: Thank you, Dr. Kelly!

* General principles apply to those on HEN, but some specific variability is not addressed in this article. For example, dehydration is affected by the amount of water in specific formulae, and osmolalities of different formulae are variable and have a big impact.

More Resources
MY HPN module 3, “Fluid Balance”: This online module (available at www.oley.org/Education_Module1.html) will teach you how to reduce your risk of developing dehydration or overhydration, as well as appropriate actions to take if one of these complications does occur. An HPN Nutrition Monitoring Log (which can be modified for HEN) is available as part of the module (or go directly to www.mdinformatics.com/MYHPN/Part3/HPN_monitoring.pdf).

For more tips on diet and hydration, go to www.oley.org/Diet_Hydration_Nutrition.html.

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And So Will You!

You’ll be smiling when you see how sweet and easy it is to order through Amazon Smile and have a portion of the proceeds go to the charity of your choice—the Oley Foundation. It’s as simple as going to http://smile.amazon.com/ch/13-3194182 and setting up a login.

It looks and feels exactly like Amazon, and picks up your Amazon account information and preferences if you have an account already established. Thanks for thinking of Oley as you shop online.
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 this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2014 in the March/April 2015 issue. From March 15 to May 9, 2014, gifts were received:

In Honor of Dr. Darlene Kelly
In Gratitude to Matt Shaw and Diane White-Shaw
In Memory of Mariah Abercromie; Peggy Bosworth; Sylvia Hermosillo's mother; Mary Patnode

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

Join the Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference at (800) 776-OLEY.

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Thank You!
Oley Ambassadors

Want to speak with someone who has “been there, done that”? Call an Oley Ambassador. You’ll find a complete list of Ambassadors at www.oley.org or (800) 776-6539. Note: Ambassadors volunteer to provide peer support for HPEN patients and family members. They are not medical professionals and do not offer medical advice.

Meet our newest Ambassadors!

Samantha Bye

Sammi Bye, as friends and family call her, is sixteen years old. She enjoys creating meals for her family, scary movies, reading sci fi mysteries, gardening, crafting, raising African aquatic frogs, using technology, and traveling to exotic places.

Sammi is the youngest of four children. She has lived with medical challenges her entire life. She has been on home parenteral nutrition (HPN) continually since 2007; prior to that she had a jejunostomy for enteral feeds (HEN). Sammi’s GI issues are related to autoimmune enteritis and intestinal dysmotility. Her medical issues also involve hemophagocytic lymphohistiocytosis (aka HLH, a rare complication of her autoimmune disease) and pulmonary alveolar proteinosis. She has been through a complicated bone marrow transplant and a relapse of HLH, and has encountered many other complications and rare disorders in relation to her condition.

Despite her medical issues, Sammi is a Warrior Princess and Kitchen Diva. She enjoys helping others adapt to and live with their medical challenges. You can reach out to Sammi via text at (609) 412-7083 or email at sammid97@aol.com.

Caryn Goldstein

Caryn Goldstein was diagnosed with Crohn’s disease at age fourteen, and developed short bowel syndrome (SBS) secondary to surgeries she’d had for her Crohn’s at sixteen and eighteen. She was treated with home enteral nutrition (HEN) intermittently as an adolescent and a young adult. In 2008-09, a serious flare of her Crohn’s disease, in combination with her SBS, resulted in numerous complications and PEG-J feedings became permanent.

“Oley was my guide throughout these past six years,” Caryn says. “I wanted to give back to Oley and my community as an Oley Ambassador.” Caryn says she found a wealth of information and support from the Oley Foundation Web site, the Lifeline newsletter, and Oley Ambassadors, including Aliza Chana Zaleon and Tina Jackson.

She also credits her adjustment to life on HEN to a sense of humor, a good support system, and the practice of Taoist Tai Chi. Caryn notes, “I look forward to helping fellow Lifeliners.” Caryn lives in Louisville, Kentucky. She can be reached at (502) 416-7434.