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LifelineLetter

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

Thoughts from a First-Time Conference-Goer

Jodee Reid

Packing up for four days in Florida is no easy feat with a parenteral nutrition-dependent child. The only consolation was that we were heading to the Oley conference and, if we forgot essential medical supplies, someone else was bound to have what we needed.

From New Zealand to Florida

Matisse had been born with chronic idiopathic intestinal pseudo obstruction and her only chance of survival was to be put on 24/7 parenteral nutrition (PN). We lived in New Zealand, a country of just four million people and very few on home PN, and were very isolated. I, of course, found Oley on the Web. I was envious of those who could meet to discuss and share experiences in person! It was a dream of mine to attend an Oley conference.

About four years ago my husband and I made the difficult decision to come to the United States so Matisse could be put on a waiting list for a small bowel transplant. So here we were in Pittsburgh, waiting for organs and just a short flight from Florida, the location of the 2009 Oley Consumer/Clinician Conference.



Matisse and Jodee at the Oley conference

Not sure that I was really willing to make the trip on my own with my chronically ill child, I applied to Oley for a first-time conference-goer travel scholarship. I didn't really expect to win. A few weeks later I received a phone call from Cathy Harrington in the Oley offices, telling me that we had won a scholarship—wow! No more excuses!

Conference Packet Inside!

Check out the 2010 Oley conference packet in this newsletter. For program updates and a registration form visit www.oley.org or call (800) 776-OLEY.

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Managing the Symptoms of Dry Mouth

Stuart A. Kay, DDS

Many home parenteral and enteral nutrition (HPEN) consumers complain of dry mouth, or xerostomia. Dry mouth appears to be an indirect consequence of HPEN, a consequence of the underlying condition that leads to HPEN therapy, and/or a side effect of medications HPEN consumers may take. Although xerostomia may not be the most significant problem related to parenteral and enteral nutrition, it can go a long way to diminishing quality of life. Moreover, there are important consequences of dry mouth that can negatively impact both oral and systemic health.



I know. For six months HPN became the central focus of my life as my physicians struggled to close multiple draining enterocutaneous fistulae resulting from a lifetime of Crohn's disease and numerous post-surgical complications. Prior to HPN I had a relatively mild dry mouth, but it became far worse during this

six-month period—whether due to HPN or to not eating, I'll never know. Although as a practicing oral surgeon I had treated many patients suffering from dry mouth, it wasn't until I became the patient that I began to understand what dry mouth really meant to my patients, and how much they suffered as a consequence of too little saliva.

Let's take a close look at the many aspects of dry mouth, with the ultimate goal of developing some useful strategies to alleviate many of its symptoms. First, we need some background information on saliva.

Saliva Plays Important Role

Although saliva is 99 percent water, it has a number of other components that play important roles. Electrolytes contribute to the buffering capacity of saliva and help in the remineralization of tooth enamel; enzymes

Dry Mouth, cont. pg. 2

Dry Mouth, from pg. 1

start digestion of starch and fat before food is swallowed and kill bacteria; mucin proteins assist with lubricating oral soft tissues (i.e., lips, tongue, and cheeks); and opiorphin is a natural pain-killing substance.

LifelineLetter

March/April 2010 • Volume XXXI, No. 2

Publisher:

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Subscriptions:

The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically.

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 Editor at the address above.

Saliva is produced by the parotid, sublingual, and submandibular glands, as well as hundreds of minor salivary glands found in the palate, lips, and other structures of the mouth. Normal daily output of saliva is approximately 1 liter per day, with salivary flow fluctuating by as much as 50 percent with our daily rhythms. The quantity and quality of our saliva are in part dependent upon normal nerve functioning. When we're calm, our parasympathetic nervous system induces more watery secretions. When we're under acute anxiety or stress, sympathetic nerve stimulation produces a sparser, thicker salivary flow, leading to sensations of dryness.

Functions of Saliva

Saliva is necessary for a healthy and normal mouth. Saliva serves multiple functions in addition to those mentioned above:

- Saliva helps maintain a neutral oral pH, thereby neutralizing potentially damaging acidic foods and liquids.
- Salivary lubrication of our oral tissues keeps them intact, thereby protecting these tissues from bacterial invasion and infection.
- Minerals in saliva can repair microscopic tooth decay. In addition, the mechanical action of saliva is important in helping wash food and debris away from our teeth and gums, a function important in preventing decay and periodontal/gum disease.

• Saliva facilitates swallowing by lubricating our food. Further, in making our food soluble, it makes it available to the taste buds located in the back of our tongue. It is an important factor in our ability to taste normally.

• Normal salivary lubrication facilitates speech.

• Saliva decreases the amount of plaque (thin bacterial film) on our teeth, thereby reducing the risk of periodontal disease.

• Proper salivary flow reduces the risk of fungal overgrowth in our mouths. Specifically, saliva helps prevent the development of oral candidiasis.

Common Signs and Symptoms

We all know what a parched mouth feels like. Clearly it's an uncomfortable, unpleasant sensation. There are, however, very specific signs and symptoms that correlate with hyposalivation (a decrease in or lack of salivary

flow). Here are some of the more common signs and symptoms of too little saliva:

- A sticky, dry feeling in the mouth or throat
- Trouble chewing, swallowing, or speaking
- Burning sensation of the tongue, lips, or cheeks
- A sensation of a loss of or altered taste
- Saliva that seems thick and stringy
- Bad breath
- A rough, dry tongue; tongue often feels cracked or excessively fissured
- Cracked lips, often with sores or split skin at

Salivary lubrication of our oral tissues keeps them intact, thereby protecting these tissues from bacterial invasion and infection.

the corners of the mouth

- Increased and persistent plaque on the teeth; teeth feel "slimy" and unclean

- An increase in tooth decay, especially along the gum line

- Evidence of the fungus *Candida albicans* (thrush) in the mouth or throat (manifestations include excessive

redness of oral tissues; white, curdlike patches that stick to the tongue and cheeks and result in bleeding if rubbed off; inflamed and often painful fissures at the corners of the mouth)

Causes of Dry Mouth

Many articles, and even some textbooks, examine the myriad causes of dry mouth. Here we'll look at some of the major underlying reasons for dry mouth, with a special emphasis on how PEN may indirectly contribute to the problem.

Lack of Chewing

In preparing for this article I had a conversation with Dr. Leo Sreebny, one of the world's foremost experts on dry mouth. After learning who would be reading this article, Dr. Sreebny immediately yelled into the phone, "Chew...tell them to chew." According to Dr. Sreebny, chewing is critical to stimulating normal salivary flow. Chewing, whether you swallow or not, initiates reflexes that lead to salivation. No chewing leads to minimal, if any salivary flow.

Medications

Dry mouth is a common and significant side effect of over eighteen hundred drugs, both prescribed and over-the-counter, in more than eighty drug classes. According to Dr. Sreebny, this is the number one cause of xerostomia in the world today. As a general rule, the greater

Dry Mouth, cont. pg. 8 ➤

Tube Talk

Send your tips, questions, and thoughts about tube feeding to:

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



Stand Frees Hands

When John Pappas realized he'd have to rely on enteral nutrition (EN) long-term, he developed a tube-feeding stand to help him be more independent. The stand is for gravity (as opposed to pump) feeding. The homeEN consumer places formula in a cylinder attached to the stand, which is attached to tubing and the consumer's G- or J-tube.



The stand is designed to free up the homeEN consumer's hands. One homeEN consumer, who has developed a stand similar to this one, explains that a stand has saved her hands from stress damage and, she adds, when using a stand she can "talk and eat at the same time!"

Find details about the SelfTube Feeder at www.selftube-feeder.com. The stand, made of plastic tubing and molded fittings, costs \$45 plus shipping and handling.

Suggestion submitted by Dee & John Pappas, selftube-feeder.com. Information taken from Web site and adapted by Lisa Metzger, Oley staff member.

Equipment-Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer use? Check out the Oley Foundation's Equipment-Supply Exchange!

A full listing of items available—from tubing and bags to formula to durable items—is posted on the Oley Web site. This list is updated every Monday, so check frequently. If you see something you need, or want to donate something you don't need, contact Oley volunteers Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351 between 9 a.m. and 4 p.m. EST. When e-mailing a request, be sure to let them know which item you are requesting and give a reference/reorder number if it's available.

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Oley at Clinical Nutrition Week

In February, several Oley members joined Oley staff at Clinical Nutrition Week (CNW) in Las Vegas. CNW is the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). Everyone came together to attend an intestinal failure research workshop, help out at the Oley exhibit, and participate in a roundtable discussion designed to help clinicians understand what it means to live on home parenteral and/or enteral nutrition (HPEN).

The intestinal failure (IF) workshop featured speakers from around the world discussing some of the latest research in IF. It was an intense two days of lectures, during which a tremendous amount of information was conveyed. Some of this research will be covered here in the *LifelineLetter* over the coming months.

One of the highlights of CNW was seeing Oley members Marshall Koonin and Susan, his daughter, receive the Lyn Howard Patient Advocacy Award on behalf of the late Lee Koonin. Lee was one of the first patients on HPN and was widely recognized for her advocacy on behalf of HPN consumers. Frustrated at the lack



Susan Koonin (left) holds the award honoring her mother, the late Lee Koonin. With her are Lyn Howard, MD, and her father, Marshall Koonin.



Zac Colton, Marshall Koonin, and Pat Brown, RN, participating in the Oley-sponsored roundtable.

of information available to those who may benefit from HPN, she and her husband Marshall started the Lifeline Foundation in the late 1970s. In 1983, the Lifeline Foundation was merged with the Oley Foundation. Lee passed away in November 2009. Another highlight was the Oley-sponsored roundtables, where consumers helped conference attendees understand the triumphs and challenges of HPEN, from the consumers' perspective. It was a lively discussion. Clinicians listened with interest as Oley Foundation President Rick Davis, joined by Oley members Terry Edwards, Mariah Abercrombie, Felice Austin (Mariah's mom and coordinator of Oley's Regional Coordinator program), and Zac Colton spoke from the heart about some of the trials they have faced, and how consumers and clinicians can improve communication.

A third highlight was seeing the hard work of Oley Trustee, Laura E. Matarese, PhD, RD, LDN, FADA, CNSD, recognized with the Excellence in Nutrition Support Education award. Congratulations Laura!

Next year the meeting is being held in Vancouver, B.C. Mark your calendar and plan to join us from January 30 to February 1, 2011.

*Congratulations to
Laura E. Matarese, PhD, RD*

of information available to those who may benefit from HPN, she and her husband Marshall started the Lifeline Foundation in the late 1970s. In 1983, the Lifeline Foundation was merged with the Oley Foundation. Lee passed away in November 2009.

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HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our consumers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org.

Vanderbilt University Medical Center, Intestinal Rehabilitation Program, Nashville, TN

The Intestinal Rehabilitation Program at the Vanderbilt Center for Human Nutrition provides evaluation and nutritional care to undernourished patients and patients with intestinal failure. The center has extensive experience in providing care to patients with short bowel syndrome, inflammatory bowel disease, malabsorption, fistulas, radiation enteritis, bowel obstruction, ischemic bowel disease, and eating disorders. The center's mission is to deliver high quality care through the combined efforts of a multidisciplinary team of health and research professionals.

Physician and nurse practitioner nutrition specialists work closely with dietitians, nurses, and pharmacists to offer medical evaluation, nutrition assessment, individualized interventions, and follow-up monitoring. Therapeutic intervention and management includes surgery for intestinal reconstruction, medications to optimize nutrient absorption, placement of feeding tubes, and placement of central venous access devices. Psychosocial issues are addressed by experienced individuals who work in the program. Long-term monitoring is available for consumers who require HPN, parenteral fluids, HEN, and specialized dietary modification. A primary goal of the program is to minimize the patient's dependency on HPN. The program cares for an average of forty to fifty HPN patients.

The Center for Human Nutrition staff includes Douglas L. Seidner, MD, FACG, CNSP, Director, gastroenterologist; Brian Collier, DO, CNSP, FACS, Co-director, surgeon; Jose Diaz, Jr., MD, CNS, FACS, FCCM, surgeon; Lawrence Gaines, PhD, psychologist; Vanessa J. Kumpf, PharmD, BCNSP, pharmacist; Amy C. Lynch, MS, RD, CNSC, LDN, dietitian; Kimberly Currier, RN, MSN, NP, nurse practitioner; Pennie Bell, RN, research nurse; and Janet Parks, RN, nutrition support nurse.

A Day on Capitol Hill

Alan Robinson

In March, I joined Oley Executive Director Joan Bishop and a group of Oley consumers to participate in two days of education and lobbying on behalf of the Digestive Disease National Coalition (DDNC) at its 20th annual public policy forum. The DDNC is a coalition of eleven professional and patient groups who have an interest in what are generally difficult to diagnose, difficult to treat, and often disabling digestive diseases.

All of the participants had a common interest in pushing changes in law that (1) promote research and early detection programs that could help patients diagnosed in the future; (2) change Medicare, Medicaid, and Social Security disability rules that would allow patients to get the care and financial support they need without entering a skilled nursing facility.

Nearly 150 people formed 17 teams that completed over 70 meetings with the staff of U.S. Senators and Representatives. These meetings were informal and provided an opportunity for Congress to hear from patients who face challenges in trying to make their digestive tracts work well enough for them to survive. The impact was powerful.

The legislative goals of the DDNC are broad, which is not surprising given the broad range of organizations represented. The full list of legislative and governmental actions that the DDNC supports can be found on their Web site (www.ddnc.org/about.asp). Additional information on individual bills can be found by searching the Library of Congress Web site (thomas.loc.gov/).

After the two days, I learned that few of the concerns of the coalition were addressed in the health care reform proposal then before Congress. In particular, the DDNC's goals relating to Medicare and Medicaid paying for infusion therapy were dropped. Those legislative priorities relating to funding research or pilot projects for patients will be decided within the next two or three months as the budgets are discussed in the committees that until now have been tied up dealing with the health reform. All other legislative priorities will begin working their way through Congress and many could be added as part of budget reconciliation bills that will work their way through Congress in the fall.

After my meetings, I believe that DDNC's legislative goals have the best chance of passing Congress if each of us with the ability to e-mail, write, or call our Representatives and Senators takes the time to do so in support of one or more of the coalition's legislative goals.



Join Oley on 

Hear the latest news, learn about upcoming events, and chat with friends. It's easy to find us. Just type "Oley Foundation" into the facebook search box. We'll see you there!



**ThriveRx
Calendar
Contest**

Send us your photos!

ThriveRx is holding a calendar contest for consumers on home enteral or parenteral nutrition. Twelve winners will be selected. Entrants will be judged on the best picture showing themselves "living life on nutrition support." Please send your high resolution jpeg photo to Info@Thriverx.net by June 1, 2010. Be sure to include the person's name, phone number and email address.

All proceeds for the calendar will go directly to support the Oley Foundation.

To view slides from our last webinar, *Trace Minerals in Intestinal Disease*, please visit www.thriverx.net. Our next webinar will be held in June...more information to come!



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Nutrition and You

Got Sunshine?

This is the second of a two-part series on vitamin D (cholecalciferol).

In our last column we discussed the importance of vitamin D, the so-called “sunshine vitamin.” Vitamin D has many functions including promoting calcium absorption in the gut and maintaining adequate serum calcium and phosphate concentrations to enable normal mineralization of bone. Vitamin D also plays a role in bone growth and bone remodeling by osteoblasts and osteoclasts, and protects against osteoporosis in older adults. We now know that vitamin D has other roles in health, including regulating the immune system and reducing inflammation. In this column we will discuss risk factors for vitamin D deficiency, and the benefits and risks of vitamin D supplementation.

Are You at Risk for Deficiency?

People who may be at risk for vitamin D deficiency are those who have little exposure to ultraviolet light from the sun (or a tanning bed), and people who consume little or no foods that contain vitamin D, such as oily fish (i.e., salmon, sardines, mackerel, tuna), fish oil, or foods fortified with vitamin D (like milk, milk products, and cereals). In addition, certain medications (such as glucocorticoids and

antiepileptic drugs) can reduce your vitamin D, and certain conditions (such as advanced /chronic liver or kidney disease) can reduce the conversion of vitamin D to its active metabolite in the body.

Adults on home enteral nutrition receive the Recommended Dietary Intake (RDI) of 400 IUs or more per day in 1500 ml of commercial formula. Children on enteral nutrition receive the minimum RDI (400 IUs) in 1000 mL of formula (ages 1 to 8), and 1500 ml of formula (ages 9 to 13). People who receive home parenteral nutrition receive the parenteral equivalent of the RDI of vitamin D in their daily multivitamin infusion (200 IUs adults, 400 IUs children). However, many researchers feel that the RDI of vitamin D may be insufficient, and that both adults and children may benefit from a higher amount. How much more should be based on the individual’s level of active vitamin D, which is measured by their level of serum 25-hydroxy vitamin D. At the 2009 parenteral micronutrients conference, Hector DeLuca, MD, a world expert on vitamin D, recommended 25-hydroxy vitamin D serum levels at a minimum of 30 ng/ml and no more than 100 ng/ml for all adults. This level is recommended for children, as well.



To determine your risk of vitamin D deficiency, ask yourself:

- How often do you venture outside? Do you receive any ultraviolet light daily?
- Do you take in at least the minimum amount of your enteral feeding to meet the RDA for all vitamins and minerals?
- Do you receive home parenteral nutrition daily with the multivitamin included?

If you answered “no” to any of these questions, you may be at risk for vitamin D deficiency.

What About Toxicity?

It is possible to get too much of a good thing? An excess of vitamin D (hypervitaminosis D) can cause high blood concentrations of calcium (hypercalcemia), which can cause overcalcification of the soft tissues, heart, and kidneys. It can also produce kidney stones, and can result in hypertension. Hypervitaminosis D symptoms appear several months after excessive doses of vitamin D supplementation.

What Should You Do?

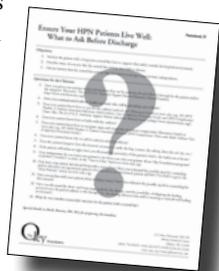
Ask your physician to check your status by measuring your serum 25-hydroxy vitamin D level. If you are deficient (below 30-100 ng/ml), you and your physician can decide the best method of replenishing vitamin D, whether that is adding an oral or enteral vitamin D supplement. (IV vitamin D is not available as a separate product.)

Since vitamin D has multiple functions in the body, it is worth determining your vitamin D status whether you are an HPEN consumer or a care provider to ensure you maintain a healthy level.

This column has been compiled and reviewed by Carol Ireton-Jones, PhD, RD; Laura Matarese, PhD, RD, LDN, FADA, CNSD; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, PhD, RD, CNSC.

New Clinician Resources

Brand new for clinicians is a handy reference they can use when sending patients home on parenteral or enteral nutrition. Entitled, “Ensure Your HPN/HEN Patients Live Well: What to Ask Before Discharge,” the reference sheet provides a list of questions and suggested resources designed to help clinicians identify and address the many issues consumers face when being discharged on home IV or tube feeding. A huge thanks to the author, Sheila Messina, RN, MA, for developing this valuable resource. Free copies are available at www.oley.org, or by calling (800) 776-OLEY.



A second resource, designed to help professionals quickly find the materials most pertinent to them on the Oley web site, is the new “For Clinician’s” page. Check it out at www.oley.org/clinician_materials.html.

Pediatric Rehydration

Baxter International, Inc., has announced the commercial launch of Hylenex recombinant (hyaluronidase human injection) for use in pediatric rehydration. Hylenex, an enzyme, allows fluids to be administered under the skin (subcutaneously) rather than through a vein. This may be an option for children who need hydration in whom IV access is an issue and in whom enteral nutrition will not work.



Thank You Baxter Healthcare

A warm thanks to everyone who stopped at the Baxter Healthcare exhibit at Clinical Nutrition Week and had their photo taken. Baxter contributed \$10 to the Oley Foundation for each photo, for a total of \$5,000. At the end of the conference, Baxter presented Oley with a big check! Pictured, from left to right, are: Oley Executive Director Joan Bishop, Oley President Rick Davis, Baxter Senior Marketing Manager Tom Dovas, Baxter Group Marketing Manager Mylene Salamero, and Oley Treasurer Laura Ellis.

More About Baxter

Baxter Healthcare Corporation has more than seventy-five years experience in developing parenteral nutrition solutions that work together to improve patient outcomes. According to the company, "Baxter offers clinicians and patients the broadest portfolio of parenteral nutrition in the industry that includes CLINIMIX Injections, an innovative commercially manufactured multi-chamber bag of parenteral nutrition formulations." Baxter also offers INFUVITE multiple vitamins for infusion (Sandoz Canada Inc.); lipid emulsions for infusion; AUTOMIX 3+3 and MICROMIX automated compounding equipment; and LOGIX compounding software. Parenteral nutrition solutions from Baxter efficiently help professionals meet the nutritional goals of patients. More information about multi-chamber bag PN is available at www.clinimix.com.

Have Your Questions Answered

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

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

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

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

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



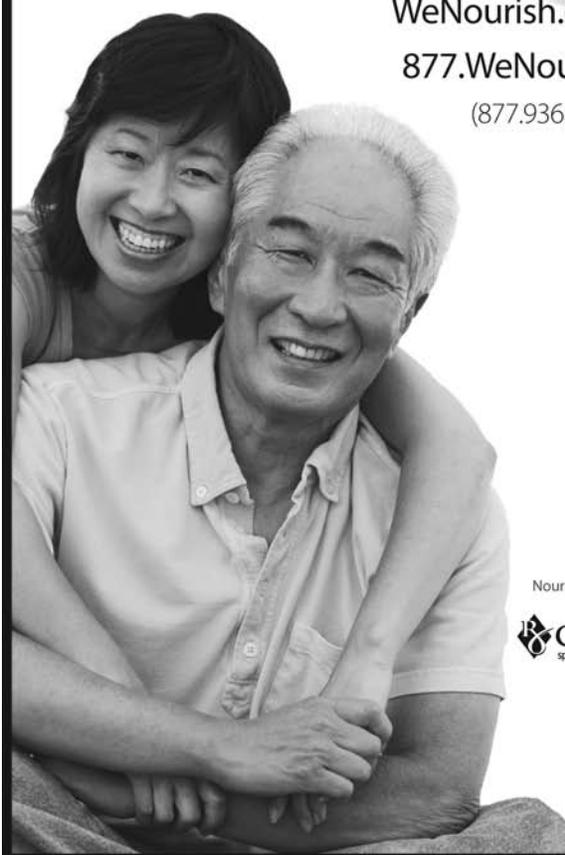
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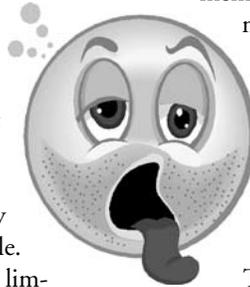
Dry Mouth, from pg. 2

the number of drugs being taken, the greater the risk of developing dry mouth. Common classes of medications that frequently result in dry mouth symptoms include antihistamines and other anti-allergy medications, decongestants, cardiovascular drugs for hypertension, antidepressants, sedatives, painkillers, antacids, anti-Parkinson's medications, muscle relaxants, and antiemetics.

Medication-induced dry mouth may result from neural effects to the salivary glands which are generally reversible. Although eliminating the offending medication will likely improve salivary flow, stopping an offending medication is often not possible. We'll examine other strategies that may be effective when we look at solutions to dry mouth.

Systemic Disease

A number of systemic diseases are associated with dry mouth, Sjögren's syndrome being perhaps the most notable. Primary Sjögren's syndrome (pronounced "showgren's") is limited to the eyes and salivary glands, producing both dry eyes and dry mouth. Secondary Sjögren's syndrome is associated with autoimmune or connective tissue diseases, i.e. rheumatoid arthritis, systemic lupus erythematosus, and systemic sclerosis (scleroderma). Other autoimmune diseases associated with dry mouth are fibromyalgia, chronic fatigue syndrome, and Raynaud's phenomenon. In addition, the following are frequently associated with complaints of dry mouth: chronic active hepatitis, HIV, AIDS, bone marrow transplantation, renal dialysis, diabetes (especially when poorly controlled), graft-versus-host disease, vasculitis, and primary biliary cirrhosis.



Radiation Therapy

Cancer of the head and neck regions, including the oral cavity, nose, sinuses, "throat" (larynx and pharynx), and esophagus is often treated with radiation therapy. Radiation therapy can injure both major and minor salivary glands. As a consequence, the salivary glands atrophy, resulting in varying degrees of either temporary or permanent dry mouth.

Dehydration

Fluid loss is often an everyday struggle for many Oley Foundation members. Even though I am no longer on HPN, fluid loss through my ostomy continues to be part of my reality, a part that needs my careful attention. Dehydration, of course, is the inevitable result of poorly managed fluid loss, with all of its signs, symptoms, and systemic effects. Dry mouth will almost always be one of the signs of dehydration. Happily, adequate hydration will quickly reverse this cause of dry mouth.

Depression and Stress

To be human is to experience anxiety, stress, and depression. Add the need to manage daily HPEN, as well as our individual health problems, and stress can easily become a frequent companion. One of the consequences of chronic or acute stress and depression is dry mouth. Although clearly not the most urgent stress-related problem, dry mouth can exacerbate the stress and anxiety we're already feeling. To make matters worse, many of the medications used to treat anxiety and depression, i.e. selective serotonin reuptake inhibitors (SSRIs), often have dry mouth as a frequent side effect. Developing healthy strategies and coping mechanisms that can reduce our everyday anxieties and stress to manageable levels will

Helping TPN consumers live independently

I'm stubborn and my husband says I'm a pain in the butt. We've been married 29 years and are more in love than the day we married. I love my friends, enjoy gardening, traveling and partying. Right now I am into redecorating everything.

Message to others on TPN

You have to breath, you have to sleep, you have to do TPN. It's just another thing you do. Get over it, get it done and move on to the fun stuff. Every moment is a gift.

About Nutrishare

Nutrishare brings my stress level way down. They take care of my needs as if they were their needs. And if a problem or crises comes up Nutrishare is all over it like sugar on a doughnut.

Susan

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The Oley Foundation

I AM NUTRISHARE



SUSAN O'BERSKI

not only help elevate our quality of life, but may also help to reduce our sensations of a dry, uncomfortable mouth.

Strategies for Relieving Dry Mouth

For most of us with problems requiring HPEN, the causes of dry mouth are numerous and complex. Solving one reason alone for dry mouth is unlikely to eliminate the problem. As with many chronic health problems, managing rather than curing the problem of dry mouth is generally more realistic. Happily for most of us, strategies exist that can reduce this unpleasant problem so it no longer interferes with our quality of life.

Medications

As noted earlier, the medications we're on are often a major cause of dry mouth. The greater the number of these drugs taken per day, the greater the oral dryness. Given these facts, what strategies are available to help diminish the negative impact medications may have on our oral tissues?

First attempt to identify what drugs may be causing oral dryness. Your physician may be able to help identify the offending medication. The following Web site will also help you identify most medications that produce a dry mouth: www.drymouth.info/consumer/SearchForDrugs.asp. Discuss with your physician possible substitutions that may have less of an oral drying effect.

Many of us have several medical caregivers, who each prescribe different medications. Make sure all your caregivers are aware of all the medications you're taking. It may be possible to eliminate some of the medications you're now on. Remember, the greater the number of medications, the more severe the oral drying.

In general, the intensity of oral dryness is directly related to the level of the offending drugs in the blood. The higher the blood level, the more severe the dryness. Changing the way a medication is taken may reduce the level of oral dryness. For example, dividing a prescribed dose into smaller, more frequently taken doses may reduce the dryness. It's important, however, that you first consult your physician and discuss whether you can change the dosing pattern.

The degree to which we experience oral dryness often varies throughout the day. You may find some relief by altering your drug-dosing schedule so that those times when your mouth is most dry do not coincide with taking the offending medication.

Instituting some of these strategies will likely not eliminate oral dryness altogether, and in some cases will not help at all. However, it is likely one or more of these suggestions will lead to fewer symptoms of dry mouth. It's worth a try.

Lack of Chewing

Remember Dr. Sreebny's admonition to chew? Chewing is critical to stimulating normal salivary flow. No matter what the primary cause of your dry mouth is, lack of chewing will guarantee a dry mouth. Note that I did not say "eating." It is not necessary for you to swallow food in order for chewing to be effective. Eating may not be possible if your bowel is obstructed or you cannot swallow, but chewing usually is.

The easiest and most convenient way to chew is to chew pleasant-tasting, long-lasting gum. Let's take a closer look at some of the basics of gum and gum chewing.

First and foremost choose a sugar-free gum. Gums that contain

sugar, usually in the form of sucrose, have several negative effects: (a) They produce an acidic pH to the saliva, which in turn tends to erode tooth enamel and ultimately leads to tooth decay; (b) Sucrose increases the population of decay-producing bacteria in the mouth, especially *Streptococcus mutans*.

There is some evidence that cinnamon-flavored gum may have an antibacterial effect, thus reducing the potential for dental decay and possibly even periodontal disease.

Gum with the natural sugar substitute xylitol may be the most appropriate product for those with dry mouth. Xylitol is a natural sweetener found in many fruits and vegetables. It is most often extracted from birch trees, corncobs, or other natural sources. Xylitol does not require insulin to be properly metabolized and can serve as a sugar-free sweetener for diabetics. Xylitol does not support bacterial growth, thus one of its primary benefits is decreasing the incidence of dental decay. Xylitol also reduces plaque formation, making plaque on teeth less adhesive; it neutralizes plaque acids and stimulates salivary flow; and it assists in the remineralization of tooth enamel.

In order to obtain the oral benefits of xylitol, including its salivary-stimulating effects, six to ten pieces of gum should be chewed daily, and each for a lengthy period of time. On average there is 1 gram of xylitol in a piece of gum, leading to a maximum of 10 grams of xylitol per day. At high doses, i.e. 45 grams per day for children and approximately 100 grams per day for adults, xylitol may cause diarrhea. There is no need to ingest these doses to obtain xylitol's oral benefits. [Editor's note: It is uncertain what amount of xylitol or sorbitol may cause or exacerbate diarrhea in consumers with short bowel syndrome.]

The following gums contain xylitol: Zapp! Gum; Epic Xylitol Gum; Spry Gum with 100% Xylitol; Ricochet Gum by Emerald Forest; Trident® Sugarless Gum with Xylitol (and sorbitol); Biotène® Dry Mouth Gum (also contains sorbitol). The best way to purchase some of these products may be online. You can also obtain detailed information on the ingredients in each piece of gum if you go online. Sorbitol, another sugar substitute often found in gum, has a similar benefit and similar potential to cause bloating, flatulence, and diarrhea if taken in large amounts.

Oral Hygiene

Regardless of the reasons for dry mouth, or its severity, there are a number of local procedures we can do to reduce our dry mouth symptoms, as well as to diminish or eliminate some of the negative consequence of oral dryness. Some of these simple oral hygiene strategies can help improve our everyday quality of life.

Toothbrushing and flossing: As discussed earlier, lack of proper salivation predisposes us to increased incidence of decay and periodontal disease. Without adequate amounts of saliva, sticky, bacterial-laden plaque tends to remain on our teeth. Toothbrushing and flossing therefore become especially important in the presence of oral dryness.

You should brush and floss several times each day. However, lack of adequate salivation tends to desiccate our oral tissues, making them unusually susceptible to local trauma, including toothbrushing. Use only very soft-bristled toothbrushes in order to avoid cutting and abrading fragile gums and adjacent tissues. In addition, avoid using

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For most of us with problems requiring HPEN, the causes of dry mouth are numerous and complex.

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excessive pressure when brushing. A light, gentle touch, even with the softest bristled toothbrush, will adequately remove debris and harmful plaque from teeth.

Toothpastes and mouthrinses: Using toothpastes and mouthrinses specially designed for people with increased oral dryness will avoid burning cracked, dried, sensitive lips, gums, and cheeks. Avoid products containing alcohol. Alcohol, especially in mouthrinses, will further desiccate already sensitive oral soft tissues, making them more prone to cracking, abrasions, and increased sensitivity. In addition, dry mouth toothpastes and mouthrinses should contain no sodium lauryl sulfate, a commonly used ingredient that can cause aphthous ulcers (canker sores), further damaging already fragile oral soft tissues.

The following toothpastes are recommended for people with dry mouth: Orajel® Dry Mouth Moisturizing Toothpaste; Tom's of Maine® Clean and Gentle Care SLS-Free Anticavity plus Dry Mouth Soother Toothpaste; and Biotène Dry Mouth Toothpaste. I have personally been using Biotène Dry Mouth Toothpaste for many years. It contains xylitol but not sodium lauryl sulfate, and also contains an enzyme system that may mimic the effects of naturally occurring salivary enzymes.

Rinsing multiple times daily with properly designed mouthwashes is important for removing food and other oral debris that normally would be eliminated by proper salivary flow. These mouthrinses are recommended for people with dry mouth (none listed contain alcohol): Biotène Mouthwash with Xylitol (contains the same enzyme system as the toothpaste); Oasis® Moisturizing Mouthwash; Tom's of Maine Cleansing Mouthwash; and Crest Pro-Health™.

Tongue cleaning: Lack of normal salivary flow severely compromises our ability to flush away oral debris and bacteria that accumulate on both teeth and oral soft tissues. In particular, the entire surface of our tongue, especially in the posterior regions, becomes impregnated with billions of odor-producing bacteria. Many of these anaerobic bacteria (do not need oxygen to thrive) produce volatile sulfur compounds, giving our breaths a rotten-egg odor. It is critical to clean the surface of the tongue, especially after awakening. Since most of the odor-producing bacteria lodge in the crevices at the back of the tongue, make a special effort to carefully clean this back region.

There are several methods to effective tongue cleaning: (1) You can brush your tongue with a toothbrush. While this maneuver can be effective, it's difficult to thoroughly clean your tongue with the soft toothbrushes required in oral dryness. (2) You can scrape the surface of your tongue with the edge of a spoon. This technique is often more effective than using a soft-bristled toothbrush. Rinse the spoon clean of debris after each scraping before continuing. (3) Use a professionally designed tongue cleaner or scraper. Using a specially designed tongue cleaner is by far the best method to clean your tongue. I have been using inexpensive, plastic tongue scrapers for years. They're effective and work well.

Perhaps the best strategy is to ask your dentist for particular tongue cleaner/scraper suggestions. Then ask for a lesson on the best way to use the cleaner. The tongue cleaners I have been using for more than a decade are the BreathRx® Gentle Tongue Scrapers from Discus Dental. Only dental professionals can order products from Discus Dental, so you may want to ask your dentist to help you purchase

the scrapers. However, there are many other equally effective tongue cleaner/scrapers that you can purchase directly. Just go online, search for "tongue cleaner/scraper," and you'll be on your way to a cleaner, more pleasant-smelling tongue.

Saliva Substitutes/Oral Lubricants

Despite all these efforts, our mouths may remain uncomfortably dry. Over-the-counter saliva substitutes and oral lubricants may help ameliorate the distressing sensations of oral dryness. Formulated either as solutions, sprays, or gels, the primary purpose of these products is to coat dry oral tissues with lubricants that may make chewing, swallowing, and speaking easier and more comfortable. Effectiveness varies from individual to individual, but some degree of relief from dry tissues can be expected.

Saliva substitutes are designed to mimic the chemical and physical characteristics of saliva. They normally contain a mixture of buffering agents, ions, cellulose derivatives designed to lubricate and increase viscosity, and flavoring agents. Generally lacking are antibacterial and digestive enzymes and other proteins found in saliva.

Saliva substitutes are designed to be used frequently, and unless otherwise indicated, can be safely swallowed. Oral Balance®, a gel, claims to provide hours of relief, although most saliva substitutes provide only short periods of lubrication. Some examples of over-the-counter saliva substitutes you may want to try include: Oral Balance Gel with Xylitol (Biotène); Salivart® (spray formulation); Mouth Kote® (spray formulation); Moi-Stir® (spray formulation); and Thayers® Dry Mouth Spray. You may need to sample a number of these products until you find one that works best for you.

Conclusion

My hope in writing this overview of dry mouth (xerostomia) was to help improve, even if only slightly, the lives of Oley Foundation members on HPEN. Although I've tried to be as comprehensive as possible, in reality this document represents only a first step in helping you manage one small challenge among the many you face. It's sometimes said that within each challenge lies a solution ready to be discovered and implemented. In this case, learning to more effectively manage your dry mouth symptoms may, in a small way, help you live a freer, happier, and more comfortable life. ¶

Useful Web Sites for People with Dry Mouth

Drymouth.info

www.drymouth.info/consumer/default.asp

NIH Clinical Symptom Research: Dry Mouth & Salivary Dysfunction

http://symptomresearch.nih.gov/chapter_27/index.htm

Biotène

www.Biotene.com

Mayo Clinic

www.mayoclinic.com/health/dry-mouth/HA00034

Sjögrens Syndrome Foundation

www.sjogrens.org/

Consumer Guide to Dentistry

www.yourdentistryguide.com/dry-mouth/

Notable Gifts from Individuals

Between January 21, 2010, and March 16, 2010, donations were received:

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Rick Davis's hike
Karuna Agrawal, celebrating 4 years on HPN
Sean May's 11th birthday & 8.5 years on HPN
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Jim Wittman's 60th birthday & 35 years on HPN
Don Young
Robin Lang's 30 years on HPN

In Memory of:

Richard M. Harris
Carl Taylor
Colyn Woods

In the Name of:

Lee Koonin, to remember all she did for us



Oley Horizon Society Blossoms!

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

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Conference Packet

Don't miss the conference packet
inside this newsletter!

Conference, from pg. 1

Warm Welcome

When Lesley, a Florida native and regular Oley conference-goer, heard that we would be attending the conference, she offered to collect Matisse and me from the airport. This was wonderful. I did not have to worry about trying to lug PN, supplies, and luggage into a taxi—plus Lesley has a daughter a little older than Matisse and they immediately became great friends. This is what the conference is about.

Matisse was so excited that she would finally meet others like her, she could hardly contain herself. Being a child on PN is very isolating, and she is now at an age where she realizes she is a little different.

PN Down Under

On arrival we checked into the Trade Winds Island Resort in St. Petersburg, dumped our bags, put the PN and medication in the fridge, and headed to our first meeting. It was for Oley Regional Coordinators (RCs). I attended on behalf of Brenda Dunn and Parenteral Nutrition Down Under (PNDU), representing New Zealand and Australia.

Matisse and I were a little late and quietly entered the room, trying to remain anonymous; after all, I was not entirely sure we belonged here as New Zealand and Australia were unofficial territories for me. I whispered to Joan Bishop, Oley Foundation Executive Director, that I was Jodee from New Zealand. Joan loudly announced, "And this is who I was telling you about!" Everyone in the group turned and welcomed Matisse and me. It turned out that Joan had just been telling the attendees about a small group down under (PNDU) who wanted to join Oley as an international alliance. We were warmly welcomed, and from that moment on I realized we were among friends.

Minority Are Majority

Those of us without tubes, lines, and bags were the minority at the conference, and this was great for Matisse. For me the friendships formed with other parents and the information shared by adult PNers was priceless.

I cannot believe I had debated with myself about attending the conference. I am a seasoned HPN mom now, with nine years under my belt; I am pretty confident with all things IV and was not sure there would be much at the conference that would interest me. Boy was I wrong! Although we don't often feel it, the world of parenteral and enteral nutrition is changing; new information is regularly coming to light and the Oley Foundation keeps up with these changes. The conference offers great speakers and round table events to address current issues and practices.

Matisse spent much of each day having a blast in childcare provided by Oley volunteers, which allowed me to attend these speaking events. At night we partied, with the silent auction being a highlight, as well as the Beach Party. There was never a dull moment. We came home exhausted, but totally fulfilled with knowledge and friendship.

Ready to Go Again

I realize that for many, attending an Oley conference is out of the question. However, if you are putting it off because you think it is just too hard, think again. I have already booked for this year. Matisse has been looking forward to the conference since she arrived home last year. We cannot wait! ♡



Matisse Reid