Central Venous Catheters, Biofilm, and Thrombosis
Marcia Ryder, PhD, MS, RN
This article was adapted from a breakout session Dr. Ryder gave at the 2013 Oley Conference.

Microorganisms (or bacteria) are everywhere. About one-hundredth the width of a human hair, they were the first living cells on Earth. They have had to adapt to survive over this vast time span. Ancient, invisible and powerful, bacteria cause catheter-related infections.

Bacteria's Lifestyles
In 1683, Van Leeuwenhoek developed the first microscope that was powerful enough to see bacteria. He didn’t know what he was seeing, but he observed something alive and moving. Now we use a very sophisticated microscope called a “confocal laser,” which takes real-time pictures. And while before we thought bacteria only existed as single cells, we now know there are two types of lifestyles for them.

Bacteria live as independent, single cells (which we call “planktonic”) floating in liquids, but most often they live in a biofilm, as a community of microorganisms stuck to each other on a surface. The cells in a biofilm are physiologically distinct from planktonic cells.

Biofilm
Biofilm is all around us—on showerheads, toothbrushes, water systems, in our bodies....Some of the

Patient Meeting in Nashville, November 1
In conjunction with the Oley Foundation, the Center for Human Nutrition at Vanderbilt University Medical Center will be conducting an educational meeting on Friday, November 1, for people on specialized nutrition support (enteral and/or parenteral nutrition, or HPEN). The program, entitled “Managing Intestinal Failure: Old Tricks and New Therapies,” is designed to help HPEN consumers learn how to improve their lives while receiving nutrition support therapy. The meeting will be held at the Nashville Marriott at Vanderbilt University, 8:00 a.m. to 3:00 p.m. To register or for more information, call Patsy at (615) 322-7959 or e-mail VCHN@vanderbilt.edu.

Presentations will include: “Quality of Life Issues for HPEN Consumers,” by Marion Winkler, PhD, RD, LDN, CNSD; “Managing Intestinal Failure: Diet and Medication Can Make You Better,” by Doug Seider, MD, AGAF, FACC, CNSC; and “How to Get the Most from Your TPN,” by Vanessa Kumpf, PharmD, BCNSP.

Holiday Hints
From Halloween through Valentine’s Day, fall and winter are loaded with holidays—and many seem heavily focused on food. We invited Oley members to share what they consider most stressful about holidays, and how they manage, reduce, or avoid the stress. Here are some of the responses we received. Note: HPN = home parenteral (or IV) nutrition; HEN = home enteral (or tube) nutrition.

The holidays seem to revolve around food, and for many of us that is a real challenge. I’m okay with friends and family, because they all know about my eating difficulties. But strangers or acquaintances with whom I am not as familiar often urge me to eat, to “taste this,” or question why I am sitting with just mashed potatoes on my plate.

I have developed a short, quick answer that usually puts a stop to the questioning and prodding. I say, “I have a digestive problem that severely restricts what and how much I can eat. But tell me, what are you eating?”
doing these days?” Most people are more than happy to turn the conversation to themselves, and they get the general idea.

Really, these get-togethers are about the conversation and the chance to see people we rarely see, and as long as they’re not bugging me to eat, I enjoy being in the company of others. I try to keep the conversation away from my illness, hospitalizations, and surgeries. When queried, I always respond that I am doing fine. It’s too complicated to try to explain in any kind of detail.

—Candace, Forum Contributor “candacepoer”

I have found it is best to be matter of fact. I have a feeding tube because my digestive tract does not operate in a way that allows me to get the nutrition I need from food. Like Candace said [above], a very good tactic is to turn the conversation back to them.

As far as details go, I generally tell others it is a long boring story that probably isn’t appropriate for the dinner table, but if they really want to know more about my condition(s) maybe we could get together another time. In my experience this pleases them because you are not actually blowing them off, and no one has ever followed through with it. People will only make as big a deal out of it as you do.

—Kristin, Forum Contributor “Scooby06”

Socials are always centered around food, and the holidays multiply these socials. Since I enjoy gatherings with friends, I am glad to attend and I try to eat only what agrees with me. At a recent Labor Day BBQ, I asked what was in the salad and if there was cheese in the casserole. When I heard cheese was in both, I just said, “No, thank you,” as I passed through the buffet line. There were other things I could safely eat. I also took along my oral rehydration solution to stay hydrated. For dessert, I had one spoonful of ice cream to satisfy my sweet tooth. This much I am able to get away with safely, and a taste satisfies me. I also try to keep the conversation away from my illness and offers a brief explanation about my limited ability to eat on the other, with a request that the server allow you to order a smaller portion and share a meal. Request one at www.oley.org/restcards.html or (800) 776-6539.

Card Makes Eating Out Easier

Tired of explaining why you are not ordering a full meal when dining out? Request an Oley restaurant card to help you discreetly explain. The card shows an illustration of a person infusing by tube and IV on one side, and offers a brief explanation about your limited ability to eat on the other, with a request that the server allow you to order a smaller portion or share a meal. Request one at www.oley.org/restcards.html or (800) 776-6539.
Thinking Outside the Can
An Oley member, Heidi has written several “Outside the Can” articles for MitoAction. We hope to share more of these in upcoming issues of the LifelineLetter.

Medicare does not cover supplemental enteral nutrition if taken by mouth, even if the formula is medically necessary and constitutes 100 percent of the individual’s oral intake. At this time, these same products are approved for Medicare coverage if administered through a permanently placed feeding tube, such as a PEG tube. Individuals who are privately insured sometimes have very high deductibles and copays; those who receive Medicaid may not yet be eligible to receive services. Enteral nutrition can be very expensive, and many disabled individuals simply cannot afford special formulas, which may cost several hundreds to thousands of dollars per month.

Prescription Hope
Many pharmaceutical companies offer patient assistant programs (PAPs) that distribute medication to individuals who cannot afford to purchase it. However, if a patient is on twelve different medications that are dispensed by eight different drug plans, each with their own application, it is very easy for the patient to miss questions or make clerical errors, both of which can disqualify an applicant. Prescription Hope acts as a pharmaceutical service coordinator to provide low cost medication and medically necessary nutritional supplements/enteral feeds to individuals who are uninsured or underinsured.

The Prescription Hope program has an annual $20 enrollment fee, then each month’s supply of medication or medically necessary nutritional supplement costs $20 per prescription, regardless of the wholesale cost of the medication or medical food. They provide support from your initial phone call or e-mail inquiry until the medication or formula arrives on your doorstep; the support continues as you renew your application, change to another type of formula or supplement, or no longer need/qualify for the support.

Eligibility
Eligibility requirements may change, but as of this writing (September 2013), the Prescription Hope Web site says you may be eligible for this program if you: earn $30,000 or less per year as a single person or $50,000 or less as a couple (average; some pharmaceutical company’s guidelines may be higher); do not participate in Medicaid; and are experiencing financial hardship. They also note that you may have a discount prescription drug card and still qualify.

You can obtain an application online at www.prescriptionhope.com or by calling (877) 296-4673. [Editor’s note: Terms of the agreement are outlined at the end of the application, under “Administrative Service Fees.” Please be sure you are familiar with the terms before submitting your application. Note also that you will need to communicate with Prescription Hope in writing if your prescriptions change; without written notice, Prescription Hope may continue to deliver medications as long as your contract is current.]

Available Enteral Products
Prescription Hope supports an extensive list of enteral formulas, oral nutritional supplements, and complete nutrition. At this time, these include: Elecare, Jr.; Enlive; Ensure; Glucerna; Hi-Cal Drink; Jevity; Juven; PediaSure; Polycose; ProSure powder; Promote; and Vital Jr. Please see the Web site for a full list or call to inquire about specific prescriptions and formulas.

—Heidi Martin-Coleman

More on Competitive Bidding
This is a follow-up to the discussion on competitive bidding that appeared in the last issue of the LifelineLetter. To recap, competitive bidding is a Medicare program implemented for durable medical equipment—including enteral nutrition (EN, tube feeding). Under this program, only providers that submit a winning bid in a certain area will be reimbursed for supplies and services in that area. Below is an explanation of how those bids are determined.

There have been challenges with competitive bidding since the program began in 2011. NHIA and the Oley Foundation are encouraging Medicare patients and providers who experience any issues with transitioning to a new provider to file complaints with the Competitive Bidding Ombudsman (www.cms.gov or 800-MEDICARE; search or ask for “competitive acquisition ombudsman”). Please share your concerns with the Oley Foundation as well, so we can advocate on your behalf.

Medicare determines the Single Payment Rate (SPR) for a specific product category by lining up all the “qualifying” bids from low to high. They then identify the “pivotal bid,” which is the bid that gets them to 120 percent anticipated demand. They ignore all bids higher than the pivotal bid, which could include a provider that provides high quality care.

Medicare then determines the median bid between the low and pivotal bids, and this is the SPR. The SPR does not change if suppliers that bid decide not to sign a competitive bidding contract. Centers for Medicare & Medicaid Services (CMS) may offer a contract to a bidder that was originally excluded based on the pivotal bid in order to get to anticipated demand (because some may decline to sign), but the SPR does not change. So in other words, Medicare has put cheaper pricing ahead of quality health care.

—Kendall Van Pool, National Home Infusion Association (NHIA)
Insurance, Health Care Costs, and Your Finances

Over the next few issues, we will be sharing resources and ideas related to finances and your personal health care—from organizations that offer help (as below), to details on how the Affordable Care Act might impact you (as details become known), to insights on Medicare. It’s a pretty broad topic. Please help us by sending your questions and sharing your experiences and tips to Lisa Metzger (see contact information on page 2).

Patient Access Network

Patient Access Network (PAN) Foundation is dedicated to helping patients who would otherwise be unable to afford high-cost specialty medications. PAN provides financial assistance through more than fifty disease-specific programs designed to help patients being treated for certain cancers, chronic illnesses, and rare diseases.

A full list of PAN programs is available on their Web site (www.PANfoundation.org). Of interest to many Oley members are the two PAN programs designed to benefit patients being treated for short bowel syndrome (SBS). The first provides co-pay assistance and another is dedicated to SBS patients who need financial assistance in order to pay for health insurance premiums.

PAN’s SBS Co-Pay Assistance Program provides qualifying patients with up to $10,000 to help pay out-of-pocket costs associated with prescribed specialty medications used to treat SBS. To qualify: patient must be insured; insurance must cover the medication; patient must be seeking assistance for a medication that treats SBS directly; patient must reside in and receive treatment in the U. S.; patient’s household income must fall at or below 500% of the Federal Poverty Level (about $77,000 for a two-person household). Currently, the two medications recognized as treating SBS directly are Zorptive® and Gattex®.

The PAN Foundation’s SBS Premium Assistance Program provides financial assistance for the patient’s portion of the premium associated with their insurance coverage (individual or family plan). Patients approved for the program can make the payments and be reimbursed by PAN or, depending on the employer and or payor situation, PAN can make the premium payments directly to the payor. Payment processes will be established as part of the approval process. To qualify, the patient: must be prescribed a specialty medication that treats SBS; must have access to insurance that covers this medication; and must reside in and receive treatment in the U. S. In addition, household income must fall at or below 500% of the Federal Poverty Level.

To apply, visit www.PANfoundation.org (click “Online Application”) or call (866) 316-7263; program staff are available 9 a.m.–5 p.m. (ET) Monday–Friday. PAN usually responds to a patient’s application within one business day. If a patient qualifies for assistance, PAN will send the patient an approval letter with information such as their award amount and eligibility dates. PAN will also notify the patient’s doctor and/or specialty pharmacy of the approval. If an application is not approved, PAN will contact the patient by phone to explain the decision. Approvals are for a twelve-month period, but they can be renewed if the patient remains eligible. PAN may also reimburse patients for qualifying medication expenses incurred up to ninety days prior to the patient’s approval date.

NeedyMeds

NeedyMeds is a national nonprofit organization that maintains a Web site of free information on programs that help patients who can’t afford medications and health care costs. The website, www.needymeds.org, has extensive lists of pharmaceutical patient assistance programs (PAPs); free, low-cost, or sliding-scale clinics; and drug discount coupons (as well as lists of scholarships and summer camps for people with special needs). The Web site also includes information about resources for specific diseases. All of the information is regularly updated, and accessible online at no charge and without registration. You can also call their hotline at (800) 503-6897. Representatives will help you identify the programs that may help you based on your medications and/or diagnosis.

NeedyMeds also provides a free drug discount card that offers a discount of up to 80 percent at more than 63,000 pharmacies nationwide. Anyone can use the card regardless of income level, residency, or insurance status, and no registration is required. The card never expires, and it can be used on all prescriptions (including prescribed over-the-counter medications and medical supplies), as well as pet medications. The discount card cannot be used in combination with insurance but it can be used instead of insurance if a medication is not covered, if you are in a coverage gap, or if you have a very high deductible or co-pay. You can request a NeedyMeds drug discount card through their Web site or hotline (see above).

Please also see “Tube Talk” (page 3) for information about Prescription Hope, another possible source for discounted prescriptions.

Share Your Talents

We know you’ve got talents and skills galore. We also know you’re busy—managing health issues, caregiving, working, going to school, or juggling other day-to-day activities. But if you’re inclined toward volunteering, we hope you’ll consider sharing your time and talents with us at the Oley Foundation.

<table>
<thead>
<tr>
<th>If you enjoy…</th>
<th>Maybe you could…</th>
</tr>
</thead>
<tbody>
<tr>
<td>writing</td>
<td>contribute to the newsletter</td>
</tr>
<tr>
<td>political issues</td>
<td>join in advocacy efforts</td>
</tr>
<tr>
<td>networking</td>
<td>become an Oley Ambassador</td>
</tr>
<tr>
<td>leading</td>
<td>submit your name to be considered for the Board of Trustees</td>
</tr>
<tr>
<td>technology</td>
<td>provide feedback about oley.org</td>
</tr>
<tr>
<td>graphics</td>
<td>consult on projects</td>
</tr>
</tbody>
</table>

There are many other possibilities! Please contact Joan Bishop, Oley Executive Director, at (800) 776-6539 or bishopj@mail.amc.edu.
**Bright Ideas**

**Hickman Hiders**

When my daughter Robin was diagnosed with leukemia at nine months old, I was overwhelmed and terrified with the thought of caring for her central venous catheter at home. I was dissatisfied with the available methods for containing the catheter and protecting Robin. What I found was either inappropriate for such a young patient (e.g., anything that hung around her neck or involved extra adhesive material) or prohibitively expensive.

After several months of trial and error, I developed the Hickman Hider. It is essentially a tube top (that slips over the torso, with no sleeves or straps) with a pocket, designed to fit snugly under clothes. It minimizes germ exposure (especially from the diaper area), provides a layer of protection between tubes/clamps and skin, and removes temptation to tug on the tubes.

Hickman Hiders work well for infants and toddlers with G-tubes, too, because they hide the button, and in the event of any leakage the pocket provides an extra layer of protection.

You can get a Hickman Hider online at milligear.etsy.com. If you have any custom requests or questions about sizing, don’t hesitate to contact me directly through Etsy conversations.

—Gayle G., gayle@milligear.com

**Device Helps You Grip Connectors**

MedeGrip™ is a new, small, flexible foam tool that many may find useful to help loosen tight catheter and tubing connections. It is designed to help improve your grip on the connectors. It is also designed to help protect patients and clinicians from injury when breaking glass ampoules. Designed by a vascular access nurse, MedeGrip is the first gripping device of its kind to be approved by the FDA.

The inventor of MedeGrip, Matthew Ostroff, tells us, “Our aim is to eliminate the use of unapproved tools such as hemostats on the patients’ vascular devices, as well as preventing revisits for home care agencies to remove a tight end cap. The end goal is compliance with the Infusion Nursing Society Guidelines to change end caps at the appropriate times to reduce catheter-related bloodstream infections.”

A box of 100 MedeGrips is $30; a case of 400 is $100. To order or request a sample, call (800) 652-8151 or visit www.medegrip.net.
Nutrition and You

Vitamin D: What Is It and Are You Getting Enough?

Vitamin D is well known for its role in maintaining bone health as it helps the body absorb calcium. Recently it has been investigated for its role in possibly decreasing the risk of chronic illnesses such as cancer and heart disease, and autoimmune diseases like multiple sclerosis, type 1 diabetes and osteoarthritis. It is estimated that one billion people worldwide have insufficient levels of vitamin D.

Deficiencies

Persons most at risk for vitamin D deficiency include the elderly and those who rarely spend time outside, have darker skin pigmentation, or wear sunscreen and/or clothing that covers most of the body. Sun exposure from November to February is usually not effective unless a person lives south of Los Angeles or Atlanta.

Since vitamin D is fat-soluble, fat malabsorption resulting from cystic fibrosis, Crohn's, celiac disease, and other syndromes or surgeries often results in vitamin D deficiency. Deficiency of vitamin D is defined as < 20ng/mL; insufficiency is 20–30ng/mL; and adequate levels are 30–100ng/mL. The Institute of Medicine (IOM) released new, higher recommendations for vitamin D in 2010. Nearly everyone requires 600 international units (IU) of vitamin D daily; persons over 70 years of age need 800 IU. If malabsorption or deficiency is present, higher doses are often required.

Sources

Most people get very little vitamin D from food. Milk contains about 100 IU per cup and fatty fish like tuna or salmon has about 150–450 IU per 3 ounces. Many multivitamins and calcium supplements have more vitamin D per serving than in the past in response to the prevalence of vitamin D deficiency.

It’s important to note that vitamin D is absorbed in the beginning (duodenum) and middle (jejenum) of the small intestine. Therefore, surgery or bypass of these parts of the small intestine may limit or prevent your body's ability to use the vitamin D you consume. Many people who use tube feeding (enteral nutrition, or EN) or parenteral nutrition (PN) as their main nutrition source have a vitamin D blood test to evaluate for deficiency. Since metabolic bone disease is a concern for those on long-term PN, reviewing the vitamin D level is important.

Enteral nutrition products typically provide 230–470 IU per 1000mL (about 4 cups of fluid). Parenteral nutrition includes 200 IU from the multivitamin added daily to PN. However, due to national shortages, many providers have had to restrict multivitamin use to three times per week and/or encourage PN users to consume a gummy or liquid multivitamin. The content of vitamin D can vary quite widely between different brands of gummy multivitamins. There is no parenteral vitamin D available at this time, except as part of a multivitamin. Liquid vitamin D, often in the form of drops, is a great option for people who can tolerate and absorb oral intake and can provide as much as 400 IU per drop.

Finally, when oral, enteral or parenteral intake is not enough to maintain vitamin D status, sensible sun exposure (five to thirty minutes between 10 a.m. and 3 p.m., twice per week) or use of a portable UV sun lamp, such as those made by Sperti, can be the only effective means to meet vitamin D requirements. Tanning beds are not recommended. Both the sun and tanning beds emit the two types of ultraviolet light rays, UVA and UVB. It is the UVB rays that account for the health benefits of sunshine. Most tanning salons calibrate their tanning beds to emit approximately 95 percent UVA rays, which maximizes the tanning effects of the machine and minimizes the risk of burning. Unfortunately, it also minimizes the amount of vitamin D that can be metabolized relative to the exposure to damaging ultraviolet rays.

Conclusion

Know your vitamin D level, whether you are an EN or PN consumer or a caregiver. If it is low, talk to your clinician to determine foods and supplements to increase your levels.

Written by Kristen Trukova, MS, RD, LDN, CNS, CSO, from the Cancer Treatment Centers of America, Chicago, Illinois. Reviewed by Carol Ireton-Jones, PhD, RD, LD, CNSC, and Laura Matarese, PhD, RD, LDN, CNSC. References available upon request.
Biofilm, from pg. 1

biofilms that live with us are good for us. We have over seven hundred species of bacteria in our mouth, and in the bowel, hundreds of thousands of bacteria help us digest food and absorb nutrients. All of these have jobs to do, and they help us be healthy. But biofilms on central venous access devices (we’ll use the term catheters) shed cells into the circulatory system, and these can be harmful.

How do biofilms develop? When bacteria make contact with a surface—such as a catheter—the cells make a sticky substance that allows them to stick to the surface. They then release hormone-type substances that “talk to” other cells, triggering them to produce a material that envelopes them in a cluster. This is a survival technique: in biofilm, the cells are protected from enemies. For biofilm, your white blood cells are the enemies.

Bacteria that switch into this biofilm mode—where they are cooperating and communicating with one another—change their DNA structure and how they live. For example, they down regulate, like a bear hibernating in a cave. Each cell becomes almost a completely different organism from when it started out. In this state, the bacteria are not hurting you. They are not doing anything except living in this little community.

When the biofilm reaches a mature state, however, it releases cells in order to colonize new surfaces. And if enough biofilm releases more cells than your white blood cells or antibodies can fight, you will get sick from infection.

Resistance
Bacteria in biofilm are profoundly resistant. They are resistant to host defenses (your white blood cells and antibodies) and to all antibiotics and antiseptics at the therapeutic doses we give. In order to kill biofilm cells, we would have to give ten to a thousand times the concentration of drug we use now.

Cells within biofilm can also rapidly develop antimicrobial resistance because they transfer a gene that makes them resistant to antibiotics. They also stick strongly to the surface. You have to use a lot of friction and mechanical scrubbing to get them off.

Infection and Thrombosis
When we place a catheter through the skin and into the body, we create a path for the entry of microorganisms. We also cause vessel injury (we put a hole in the vessel) and venous stasis (because the catheter will slow down the blood flow). So we now have two big potential problems: infection and thrombosis (or clotting). We’ll discuss each individually, then address the connection between them.

Bacteria can attach to the inside (intraluminal) and outside (extraluminal) of a catheter, if either are exposed to it. The most vulnerable time for bacterial attachment to the outside is during catheter insertion. Bacteria on the inside of the catheter come in through the catheter hub, from sources along your infusion set and the hub itself. Let’s talk about the outside first.

When a catheter is placed, it passes through the skin and the tissue beneath the skin, then into the bloodstream. About 250 species of organisms exist on our skin; they help maintain it as a barrier. Before the catheter is inserted, the clinician scrubs the skin with an antiseptic to reduce the number of bacteria on the skin.

Biofilm, cont. pg. 8
Biofilm, from pg. 7

Bacteria that live in hair follicles and in deeper layers of the skin, however, can't be reached with antisepsis and may attach to the catheter surface. Within hours these deeper bacteria are going to come back up around the hair follicles and the sebaceous glands and recolonize the skin. This is why we need to use skin antiseptics and change the catheter dressing on a regular basis.

Further, the open wound around the catheter will never completely heal shut; there will always be a space around it. With this open wound, there will be opportunities for the bacteria to get down in the subcutaneous tract, then into the bloodstream. This is why insertion site care is so important.

When do infections typically occur? Clinicians looked at all of the central-line–associated bloodstream infections (CLABSI) that were reported in the state of Pennsylvania in 2010. They mapped out each one of those to the day that the infection occurred.

They found that 54 of the 653 infections happened on the fifth day after the catheter was placed. Those infections were early-onset, and the early-onset infections are due to insertion and mostly bacteria on the outside of the catheter.

What about the later infections? Those are primarily from bacteria inside of the catheter. Seventy-one percent of infections happened later, during routine use of the catheter. How do bacteria get inside the catheter? They can get in through a stopcock hub, an injection port, a needleless connector, or the catheter hub itself. This is why scrubbing these surfaces before infusing is crucial. That's where you fit in. [Editor’s note: prevention techniques discussed further below.]

Thrombosis

Let’s go back to the catheter insertion. After the catheter goes through the skin, it enters the subcutaneous space. Your body will send fluids with white blood cells to the area to protect it and to begin to heal the wound. This is the inflammatory response.

Then the catheter enters the bloodstream, and proteins in the blood stick to the catheter surface. They touch the surface, turn into a solid, and begin to entrap some of the white blood cells and platelets, creating a protein or conditioning layer.

When the platelets activate, fibrin begins to build up around the protein layer, keeping the red and white blood cells together in a sheath or clot. This is the blood’s normal reaction to the foreign object—the catheter—that’s now in there. (We are working to discover catheter materials that won’t allow this to happen. The fibrinous sheath can be very small or can become quite large, blocking the blood vessel.) A “thrombus” or “thrombosis” may form. A thrombus is a clot within a blood vessel (or vein). They can form on the vessel wall due to damage to the vein wall by the catheter.

The Connection

Infection and thrombosis are distinct problems, but they are also related. Here’s how: If bacteria are present, they will form a biofilm within the conditioning layer, fibrin clot, or thrombus. These now provide added protection for the biofilm. The bacteria will say, “Yes! This is great for my community!” Bacteria have receptors and they particularly like sticking to fibrin.

We discussed how the catheter goes through the skin, then into a subcutaneous layer, and then into the blood vessel. Fibrin can develop in the subcutaneous space as well as in the bloodstream. It can create a tube of fibrin that goes along the catheter, through the tissue and into the vein. If bacteria get in that tube, they have the potential to spread through that tissue and into the blood.

You can have fibrin without having infection. If there’s no bacteria, there won’t be an infection, and bacteria don’t just “appear”—they are
transported there. You have to be very careful about doing your care so you don’t let them get inside.

Intraluminal Issues
How does biofilm get inside the catheter? I took some needleless connectors after they had been used by patients and put them under a scanning electron microscope. When I zoomed in, I saw staphylococcus in a very thick biofilm all over the top of the connector (see photo on left). Biofilm will develop on anything; if you don’t scrub the biofilm off before you inject, you’re going to flush those cells right into the catheter. Once you put those cells in there, if they touch any part of the catheter or the inside of the connector, hub or catheter, they are going to stick to it and they’re going to build more biofilm. The bacteria that don’t stick go directly into the blood.

Later I took the connector apart and scanned the flow tube. It, too, was full of biofilm cells. Again, when you infuse, these cells can be released right into your bloodstream. This is very important in terms of your care.

Blood Draws
Although we try to minimize the times we pull blood through the catheter, sometimes we have to. But when blood comes in contact with the inside of the catheter, it’s going to do the same thing it does on the outside: the plasma protein is going to stick to it and form a conditioning layer. That won’t hurt you, but if there are bacteria there, they will become a part of it.

The other problem with pulling blood into catheters is clotting, especially if your catheter is not flushed correctly. Sometimes fibrin collects at the tip of the catheter, even though blood is flowing around it. A clot inside the catheter can mean that your catheter will become blocked.

Interventions
Here are some things you can do to prevent infection:
1. Wash your hands before you do anything to your catheter. Understand the proper techniques and proper types of antiseptics to use for washing and scrubbing.
2. Protect your catheter insertion site. First scrub the area with alcohol to remove all the oils, dead skin cells, and bacteria. Then apply 2% chlorhexidine with isopropyl alcohol for complete disinfection and to delay regrowth of bacteria on the skin.

From the moment of insertion and with each dressing change, apply a chlorhexidine patch to protect against regrowth of bacteria. (The Biopatch® is the most common, but there are new products coming out.) Bacteria can’t regrow when they are exposed to the chlorhexidine. The patch will also protect against bacteria getting down around the catheter, and may help stabilize the catheter against migration.

Make sure the catheter is secure and cannot move in and out. Every time the catheter comes out a little, it picks up bacteria, and the back-and-forth motion drives bacteria down the catheter track.

3. When possible, select a connector with the lowest potential to allow bacteria to enter the connector if the bacteria have not been completely removed from the top of the connector. This is a topic I’ve been studying since 2006. The research is too detailed to summarize here, but when compared to other types of connectors, the Microclave® has consistently demonstrated the lowest risk for bacterial transfer.
4. Disinfect all connectors before you enter into them. You’ve got to disinfect anything you are going to put a syringe tip through, including

Biofilm, cont. pg. 10 →
Biofilm, from pg. 9

the catheter hub. Bacteria are on the outside of everything, as well as on the threads of your catheter hub and inside the hub.

Also, remember we said biofilm is very sticky? You’re going to need a strong antiseptic (either chlorhexidine or 70% alcohol) and you need to scrub (for how long depends on what you’re using). This was a significant change in the last version of the CDC guidelines. They used to say just wipe, but they now get the biofilm picture and they changed “wipe” to “scrub.” And you’ve got to do it every single time.

There is only one scrubbing device currently on the market. Called Site-Scrub™, it was designed for this purpose. When you put it over the needleless connector or catheter hub and twist it, it will scrub the outside, and the inside of the hub.*

5. It is better to use an intermittent push-pause method to flush your catheter. Push a little in, stop, push a little more in, stop, and keep using that method. This will not dislodge the plasma protein from the surface, but it will remove any other liquid in the catheter or any blood that has not been coagulated.

Conclusion

Vascular catheters can be life-saving and life-sustaining, but they also come with risks. It is important to know the risks and how they may occur. Understanding how to care for your catheter is an important part of your nutrition support plan. ¶

*Editor’s note: passive alcohol caps are also available, including the SwabCap™ and the Curos® Port Protector. Also, to better protect your line when you are in hospital, consider bringing a poster for your chart from the Association for Vascular Access (AVA) I Save That Line campaign, available at www.avainfo.org.

---

Conference DVDs Available

View the main sessions and highlights of the 2013 Oley Consumer/ Clinician Conference in your own living room! If you missed the conference—or were there and would like a review—borrow the DVDs to hear the experts address critical and timely issues in home IV and tube feeding. Presentations on the DVDs include:

- *How & When HPN Became an Option*, Stan Dudrick, MD, & Marion Winkler, PhD, RD
- *Becoming Your Own Advocate*, Mary Patnode, MS Ed
- *New Options for Treating SBS*, Christopher Duggan, MD
- *Engineering of Intestines in the Lab*, Khalil Bitar, PhD
- *Non-transplant Surgery for SBS*, Antonio Morabito, MD
- *Alternative Lipid Solutions*, Alyce Newton, MS, RD
- *Addressing Drug Shortages*, Mary Baker, PharmD
- *Biofilm, Thrombosis & Catheter Infection: Related?* Reid Nishikawa, PharmD, & Marcia Ryder, RN (Read the article in this issue, then watch the DVD for more details!)

DVDs are loaned for a one-week period free of charge on a first-come, first-served basis. Reserve one for a week now! DVDs and/or VHS tapes are also available for past conferences, and on a variety of other topics. See what’s available and make your requests at www.oley.org/video_dvd.html or call the Oley office at (800) 776-6539.
Scenes from the 2013 Oley Conference, Hyannis, MA
Book Corner

Tasting Life, by Lee Koonin
Reviewed by Don Young

Readers who are familiar with Crohn’s disease will recognize the long and slow path to control over this disease in the 1950s and 60s that Lee describes in Tasting Life. Yet this is not just a story of one woman’s triumph over a disease and her use of parenteral nutrition. This is a modern-day love story of sacrifice and endurance.

For those of us who knew Lee, reading this story will be like having a conversation with her. It’s not often we get such an opportunity.

In addition to being among the first people to go home on parenteral nutrition, Lee Koonin co-founded (with her husband Marshall) the Lifeliner Foundation, and spent countless hours talking to the media, professional organizations, and other patients in an effort to educate them about parenteral nutrition. These efforts are recounted in the book, as is the history of the Lifeliner Foundation, which, when it became too much for the Marshalls, was merged into the Oley Foundation.

This book is available as a download from Amazon and Apple ($8.99) or in hardcover ($20). Order a copy of the hardcover edition by e-mail to tastinglifebyinaleekoonin@yahoo.com. If you send an e-mail directly to Marshall telling him you heard of the book through Oley, he will donate part of the purchase price to the foundation (e-mail Marshall at timber285@yahoo.com).

My Voice: A Physician’s Personal Experience with Neck Cancer, by Itzhak Brook, MD
Reviewed by Paul M. Roser

I would rate this book a “10.” It is very good. It should be required reading for anyone the first time they hear head and neck cancer mentioned. Everyone should know what they are facing (except some might decline to go forward with treatment after reading it...). Dr. Brook “tells it like it is.” I could relate to many of the things he discusses. This book should also be read by every head and neck cancer surgeon, so they know what goes on after their work is finished. I would imagine many have no idea what their patients go through. As a physician and patient, this man speaks from personal “both-sides-of-the-fence” experience.

To order a copy of the book, go to dribrook.blogspot.com ($10.22 for paperback; $4.99 for Kindle download). In August, Dr. Brook also released The Laryngectomee Guide, a practical guide for laryngectomees. It, too, is available through his Web site.
Partnering with Your Primary Care Provider

Joyce Clay

In order for you to receive comprehensive medical care, it is essential that you find a physician with whom you can partner, especially if you have special needs or are medically complex. If you are a caregiver, the physician must be willing to partner with you and the patient. Finding someone to provide physical, psychosocial, and spiritual care is at best challenging for patients, their families, and the caregivers involved in this process.

Primary care providers (PCPs) who care for these special groups face challenges heightened by the complexity of the patients they serve. The limited amount of time available to a PCP makes it necessary for him or her to organize and plan prior to the encounter with the patient or caregiver. Likewise, the patient and caregiver can increase the effectiveness of the encounter by identifying their perceived priority (be it physical, mental, or spiritual) before the planned visit.

Traits to Look for in a PCP

The PCP is essential in helping his or her patients (or caregivers) navigate the health care system. The PCP who has listened well and formed a partnership with his or her patients and families is often called upon to advocate for them. From the first phone call to the comprehensive report sent to another medical system, this PCP is a key player in the care the patient receives.

The PCP with keen communication and listening skills will foster his or her relationship with patients and their families. By creating an air of openness, the PCP helps to create a positive relationship with the patient and family. As the PCP eliminates physical and emotional boundaries, patients are better able to provide and receive information. By giving the patient or family his or her full attention, the PCP helps keep the focus on the individual and/or caregivers.

The traits of a PCP willing to partner with a patient and/or caregiver include:

- Is an avid listener.
- Empathizes with his or her patients and their families.
- Spends enough time to build a trusting relationship with the individual and/or caregivers.
- Is a competent provider.
- Addresses issues in a timely manner.
- Is available, or has another team member available, when concerns are expressed.

Traits for Individuals or Caregivers to Practice

The responsibility of the patient and caregiver is also well recognized. It is unfair to think that all medical issues will be solved in one visit, or, in some cases, ever. Patients and caregivers need to be willing to provide the PCP with the medical, psychosocial, or spiritual background information that will help them or their loved one gain increased health and ultimately improve their quality of life. Additionally, individuals and their caregivers need to realize that the PCP and his or her team

are invested in the well-being of individuals and caregivers, and when setbacks occur, all members of the team feel the frustration.

Individuals and caregivers who believe they have “all the answers” have lost their objectivity, making it difficult for them to provide and gain assistance from those who want to help them with their medical and other issues. All members of the team, including the patients and caregivers, need to develop the art of listening, as much can be learned from really hearing what the person or team is trying to say.

Traits that are exhibited by individuals and caregivers who choose to partner with the PCP include:

- Collaborates with the PCP to develop a plan of care.
- Is willing to acknowledge the expertise of the PCP.
- Provides truthful answers to questions raised by the PCP and associated team members.
- Recognizes that their PCP may not always be able to make the individual or caregiver’s concerns his or her main focus.

Conclusion

In today’s medical climate, it is imperative that you work to create a strong relationship with your PCP. Ultimately, patients, caregivers, and PCPs must realize that life is a journey and the partnership forged will create life-changing results for all.

Our thanks to Joyce for sharing her thoughts on this topic. Joyce is the mother of eight children and six grandchildren. One daughter and one grandchild are medically complex.
extra stress, and higher expectations is a prolonged extra challenge. I find that I frequently fall prey to all the activity and end by spending the rest of the winter recovering. For me, the holidays are both a wonderful time of expectation and a recipe for disappointment. Each year I try to look forward to this time and plan accordingly, reminding myself that these weeks are difficult for almost everyone, even those without nutrition, diarrhea, and fatigue issues.

Acknowledging the challenge is the first step for me. I’ve been doing this for a long time and have plenty of bad experiences to learn from, but I still find it very difficult—while remaining hopeful that this year I will get it right!

Some of the accommodations I have made around preparing and planning for the holidays are to:

- **Plan ahead**—maintain my routines as much as possible, even while doing things that are unique to the holiday; keep a balance between activity and quiet time; make decisions about commitments ahead of time; plan ahead for the challenges around food; if I am going to a potluck meal, I’m sure to bring something that will be OK for me
- **Maintain responsibility for my own well-being**—keep my expectations well grounded; stay hydrated and give myself time to “rest and recover” as an important gift (rather than as a restriction)
- **Ask** (this is a difficult one) for specific help from friends and family
- **Make conscious choices about eating**—make a choice about whether I will eat a meal or just snack; decide beforehand how much and what I will eat (I am better at keeping commitments made ahead of time instead of choosing “in the moment”); have a “healthy” snack before I leave home or guests arrive so that I am not terribly hungry
- **Keep busy with other things** if I choose to restrict my eating (e.g., help the hostess, play games with children, clear the table, talk instead of eat)
- **If I throw caution to the wind, do I know where the bathrooms are?**
- **If I feel the host or hostess might be offended by my restraint (and if I know him or her well enough), I’ll have a personal conversation beforehand** without placing responsibility on him/her for my well-being or happiness

As we approach another season of holidays, I’m again trying to get it right. I have two large family gatherings at my house and this year they will be potluck. I did it all last year and spent four days in the hospital recovering afterwards. The question is only whether I learned enough. So Happy Holidays to each of you, and wish me luck!

—Mary Patnode, Oley Ambassador and President, Oley Board of Trustees

We have to remember that food is a big part of most people’s lives, and it plays an even bigger role around the holidays. It’s okay to feel sad if you can’t eat like you used to, or do the things you used to. Acknowledge your emotions and try to move past them; you’re there to see the people and not to eat cookies.

Another important thing I try to remember is that my friends or relatives may be uneducated about home IV or tube feeding, but they’re not unfeeling. I try not to take personally what other people might say because they don’t know what my life is like—living in a food-free world.

Try to make the best of an uncomfortable situation. Focus on what makes you happy; find the strengths within you that make you comfortable. It is not necessary to miss out on social events, though it takes time getting used to it. You could make your appearance after everyone has eaten so it makes it less stressful for you. Reorient your mindset and remember why you’re there. Focus on the people around you and the celebration of being with friends and family, and not on the fact that you can’t eat.

Do what is best for you and not other people (your feelings have to come first sometimes, to help you cope with what’s ahead). Be happy with the people you’re with and let this ease your tension. Chances are, the people around you are also feeling the effects of the holidays—stress and depression—though for different reasons. Take a deep breath and enjoy the moment as best you can.

—Carol Pelissier, Oley Ambassador

I recognize my limitations in speech, eating, and stamina, and compensate for my unique shortcomings. I prioritize the activities and people with whom I would most enjoy spending my “good time.” That time is defined as when I have a high level of energy and can articulate relatively well given my physical limitations.

When it comes to meals and meeting family and friends over coffee, I focus on the conversation, company, storytelling, sharing, and love. I avoid or refuse to join people in any venue that is loud or uncomfortable. For me, the holidays are both a wonderful time of expectation and a recipe for disappointment. Each time is defined as when I have a high level of energy and can articulate relatively well given my physical limitations.

As we approach another season of holidays, I’m again trying to get it right. I have two large family gatherings at my house and this year they will be potluck. I did it all last year and spent four days in the hospital recovering afterwards. The question is only whether I learned enough. So Happy Holidays to each of you, and wish me luck!

—Mary Patnode, Oley Ambassador and President, Oley Board of Trustees

We have to remember that food is a big part of most people’s lives, and it plays an even bigger role around the holidays. It’s okay to feel sad if you can’t eat like you used to, or do the things you used to. Acknowledge your emotions and try to move past them; you’re there to see the people and not to eat cookies.

Another important thing I try to remember is that my friends or relatives may be uneducated about home IV or tube feeding, but they’re not unfeeling. I try not to take personally what other people might say because they don’t know what my life is like—living in a food-free world.

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.

ThriveRx

A proud Oley Gold Medallion Partner, ThriveRx is dedicated to providing customized customer service and clinical care for the home enteral and parenteral nutrition consumer. Its mission is to ensure quality care that fosters independence and empowers patients and their families. Visit the ThriveRx Web site to learn more about its Short Bowel Program.

Nestlé Health Science

Nestlé Health Science offers nutritional and enteral delivery solutions for people with specific needs related to illnesses, disease states, or the special challenges of different life stages. Nestlé Health Science worldwide headquarters is in Lutry, Switzerland; the headquarters of its North American HealthCare Nutrition business is in Florham Park, New Jersey.
Contributor News

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 2013 in the March/April 2014 issue. From July 17 through August 22, 2013, gifts were received:

In Honor Of
Oley’s thirtieth anniversary

In Memory Of
Imagail Gordon, Eleanor Orkis, and Robert White

With Thanks
For the Equipment Exchange Program and all that Oley does

We appreciate all gifts and the 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.

Felic Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Catter
Jim Cawun
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
★ NEW! Dale & Martha Delano ★
Tom Diamantidis, PharmD
Gail Egan, MS, ANP
Selma Ehrenspreis
Herb & Joy Emich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
Deborah Groeber
The Groeber Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD, PhD, FACP
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Matarone, PhD, RD, LDN,
CNSC, FADA, FASPEN
Kathleen McNees
Michael Medwar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
Clements Pitzner
Beverly Promisel
Abraham Rich
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schenol
Doug Seddon, MD, FACG, CNSP
Judi Smith
Steve Swensen
Cheery Thompson, PhD, RD, CNSC,
& Gregory A. Thompson, MD, MS
Cathy Tokarz
Eleanor & Walter Wilson
James Witzmann
Patty & Darrell Woods
Roadine Ann & William Wu

Oley Corporate Partners

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

PLATINUM LEVEL PARTNERS
($70,000+)
BioScrip, Inc.

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

SILVER CIRCLE PARTNERS
($30,000–$49,999)
Fresenius Kabi USA
NPS Pharmaceuticals

BRONZE STAR PARTNERS
($20,000–$29,999)
Baxter Healthcare
Moog Medical Devices Group

BENEFACTOR LEVEL PARTNERS
($10,000–$19,999)
Abbott Nutrition
Home Solutions, Inc.
Kimberly-Clark
Nestlé Health Science
Walgreens Infusion Services

PATRON LEVEL PARTNERS
($5,000–$9,999)
Applied Medical Technology, Inc.
Critical Care Systems, Inc.

Thank You!

Thank You!
New Oley Ambassador

Welcome to Pam Winter, one of our newest Oley Ambassadors! Pam lives in La Follette, Tennessee. She and her husband have six children, ranging from twenty-seven to nine years of age. Pam writes, “Our youngest, Ally, became short gut in 2008 after a tumor twisted her bowel. She lost all but 25 cm of small bowel.” Since then, Ally has been off and on home parenteral nutrition (HPN), hydration, and tube feeding (enteral nutrition, or HEN). Ally has also ‘learned to do life’ with a high-output ostomy.”

Pam says, “I have learned so much and gained the courage to try different things from other Oley families. I would love to pass on our experience and be a blessing to others. There is something comforting about talking to others who truly understand this journey.”

Currently (2013) Ally is off HPN, on minimal enteral feeds, and does not have an ostomy. “I hope her success can encourage those who are just beginning the journey,” Pam adds. You can contact Pam at winterfamily8@gmail.com or (865) 585-3697.

Please reach out to Pam or any of the Oley Ambassador volunteers with your questions, or just to connect with someone in a similar situation. A list of volunteers is available at www.oley.org (select “Meet Patients,” then “Official Oley Volunteers”) or by calling (800) 776-OLEY.

Raising Awareness of HPN

To help others understand what life on home IV nutrition (HPN) is like, Oley sponsored the second HPN Awareness Week in early August. With your help, we distributed almost 2,500 awareness buttons! Visit the Oley Foundation’s You Tube page to watch the new “Living with HPN” video, as well as HPEN awareness videos by other organizations and individuals. (Search You Tube for “Oley Foundation” to find us.) Thanks to everyone who shared their story—online, in the media, on Facebook, and/or with friends and family.

We posted on Facebook and the forum each day of HPN Awareness Week. On day one we asked, “How do you describe home parenteral nutrition when someone asks about it?” Friends replied…

“I love it when I am asked what I do...So many have no idea the struggles that people requiring HPN go through—or even that it exists! So I get to share and educate [about] the technology and the blessing it is in so many lives!” —JW

“My daughter is 8. [She] tells people that her stomach and intestines don’t work, so that she gets a special kind of nutrition that goes into her blood through an IV by her heart. She often throws in, ‘No, it doesn’t hurt,’ since usually that is the first question kids ask her.” —DZ

Read more replies at www.oley.org or on Facebook. Then, mark your calendars to join us for the two 2014 awareness weeks. Contact the Oley office for ideas or to make suggestions about spreading awareness.

Make Halloween Fun for All Kids!

Offer non-food treats (as well as candy) to Trick-or-Treaters. Go to www.mommiesofmiracles.com for treat ideas and steps you can take to let families know your house is treat-friendly.

Save the Dates

Feeding Tube Awareness Week
February 9–15, 2014

HPN Awareness Week
August 3–9, 2014

Make Halloween Fun for All Kids!

Offer non-food treats (as well as candy) to Trick-or-Treaters. Go to www.mommiesofmiracles.com for treat ideas and steps you can take to let families know your house is treat-friendly.