Coping with an HPEN Life: Practical Tips for Patients and Caregivers

Tiffany Taft, PsyD, Licensed Clinical Psychologist

Editor’s note: This article was written at a very different time, before COVID-19 struck. Yet coping techniques haven’t changed. We hope something here will be helpful.

As a psychologist, I have a love-hate relationship with the word “coping.” Scientifically, coping is defined as a person’s efforts and strategies to solve personal problems, tolerate life stress, and resolve conflict. Coping skills are an important repertoire for any functioning human being to have, regardless of chronic illness identity. It may seem obvious to say what works for one person doesn’t necessarily work for the next, and to outsiders some coping strategies may seem ill-advised or downright wrong. Unfortunately, the word coping is sometimes used so flippantly it can make a person who is struggling feel even worse. “You just need to meditate” or “Just stop worrying” or …. The “just” statements can roll off the tongue without much regard for what they really mean and oversimplify the struggles a person may be facing, especially in the context of living with home parenteral and/or enteral nutrition (HPEN—IV nutrition and/or tube feeding).

Drs. Price and Levine published in the Journal of Parenteral and Enteral Nutrition, in 1979, “If, in addition to being a life-sustaining procedure, TPN [total parenteral nutrition] is to restore the psychological stability of patients, all team members must be aware of the psychosocial factors involved.” This is around the time when medicine began to shift from the biomedical model (disease focused) to the biopsychosocial model (whole person focused).

Proper handwashing is key to avoiding infections.

How to Avoid a Virus Lessons from People Whose Lives Depend on It

Anna Maria Barry-Jester, Kaiser Health News

Andrea Amelse knows handwashing.

For the past eight years, she’s been washing her hands pretty much every time she passes a sink. When she’s near a bottle of antibacterial gel, she uses it. She makes a point of avoiding people with contagious illnesses, even though it can be uncomfortable to ask to work.
Our Mission

...is to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

The Oley Foundation provides its 22,000+ members with critical information on topics such as medical advances, research, and health insurance. The Foundation is also a source of support, helping consumers on home IV nutrition and tube feeding overcome challenges, such as their inability to eat and altered body image. All Oley programs are offered FREE of CHARGE to consumers and their families.

Oley Foundation Programs

- **LifelineLetter**
- **Peer to Peer Support**
- **Conferences and Webinars**
- **Resources to Promote Living Well on Tube Feeding and IV Nutrition**
- **Equipment Supply Exchange**
- **Advocacy and Awareness**

Resource Spotlight: Webinars

Oley webinars offer easy access to great educational content—in your own home (and with the recordings, on your own time) and free of charge! You don’t need any special software, just access to the internet.

The next scheduled webinar is planned for HPN Awareness Week in October. Entitled “Superbugs: Knowledge Is Our Best Defense,” it features Kamna Giare-Patel, MS, RN, Senior Director in the Innovation Department at DSM Biomedical, and provides an overview of antibiotic-resistant organisms in clinical settings, as well as steps to minimize and prevent their propagation.

Register for this webinar or choose to watch from a list of recorded webinars at www.oley.org/webinars.

Some especially popular and/or timely webinar recordings include:

- Effective Coping Strategies
- SBS Diet, Hydration, Treatment
- Blended Tube Feeding
- Gastroparesis Treatments

Join us for a webinar, or watch a recording, soon!

How to Support Oley

Donations are tax deductible and are accepted at www.oley.org/donations or at the street address on left.
Tube Talk

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@amc.edu. Information shared in this column represents the experience of the individual and, while medical information is reviewed by an advisor, should not imply endorsement by Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.

Mom says, “Originally, a g-tube felt like defeat, but we quickly learned that it’s the opposite. It’s victory! Lennon is receiving the nourishment she needs to thrive, she’s growing, and she definitely doesn’t let anything slow her down.”

Dave shares, “This is my 20th year on tube feeding after I lost my esophagus, stomach, and some intestines due to a cancerous condition. My goals for 2020 include running a ½ marathon and remembering each day to live my best life and not borrow worry from tomorrow.”

Why an Awareness Week?

Feeding Tube Awareness Week, held each February, and Home Parenteral Nutrition (HPN) Awareness Week, held each October, are meant to:

• pull us together as a community;
• give people a way to share and participate in our community;
• create opportunities for links, between individuals and communities;
• help people feel connected and know they are not alone;
• offer hope to those who are struggling;
• increase understanding of the challenges these therapies present;
• spark dialogue and get people sharing stories;
• educate, increase tolerance, reduce stigma, and shift cultural norms.

It is not our intention, ever, to trivialize or downplay any of the significant challenges those in our community face—as consumers or caregivers—or the difficulties and dangers home tube feeding and IV nutrition present. We know these are significant, but we know, too, that you find ways to enjoy your lives despite these challenges.

2020 Feeding Tube Awareness Week

We want to thank everyone who submitted photos for Oley’s Feeding Tube Awareness video, which, as of mid-March, had almost 2000 views between You Tube and Facebook! If you haven’t seen it, watch it today at www.youtube.com/watch?v=TMe-ESOerks&t=37s. The photos on this page are from the video.

Our thanks, too, to everyone who shared Feeding Tube Awareness buttons. We distributed close to 1000 buttons this year. They were distributed and worn by consumers and families, clinical teams, home care company representatives; given out, for example, by students sharing their stories with classmates, and adults sharing their personal stories with professionals in the tube feeding industry.

Please think ahead to 2021. We’ll do another video, because we love seeing all of your photos and hearing from you. Send them anytime to Lisa’s attention at Oley’s gmail address, where large files won’t get bounced (oleyfoundation@gmail.com). It’s never too early! Include your first name and last initial, diagnosis if you are willing to share it publicly, and tell us something about yourself. What does tube feeding mean to you? What would you want others to know about tube feeding and/or your diagnosis? What is your biggest challenge, or greatest success related to tube feeding?

For 2021, consider now how you might want to get involved. Some things will require advance planning:

• Do you want to share your story with local media? Help your home care company or clinical team better understand what tube feeding means to you? If you want to contact your local media, or speak at an in-service for your home care company or hospital, we can help. Give us a call!
• Do you want to participate in advocacy efforts related to tube feeding? Again, give us a call, and we can discuss what might be on the legislative agenda at that time and what you can do.

We are here to support you. Questions? Contact Lisa at metzgel@amc.edu, (518) 262-5079, or The Oley Foundation, Albany Medical Center MC-28, 99 Delaware Ave., Delmar, NY 12054.
A Day on the Hill
Lisa Crosby Metzger

A short time before travel advisories were issued due to COVID-19, Oley members, staff, and supporters joined members, staff, and supporters from other, like-minded organizations in Washington, D.C., for the Digestive Disease National Coalition (DDNC) Spring Public Policy Forum. We spent the first day listening to an impressive lineup of representatives from: the Food and Drug Administration (FDA) and Patient-Centered Outcomes Research Institute (PCORI); companies that are developing treatments for digestive diseases; and fellow DDNC member organizations. We learned about legislative issues of interest to the DDNC community and any pending bills that could address those issues. The next day, we visited legislators’ offices as smaller groups, using what we’d learned and what we already knew to help legislators understand why they should support these bills, as well as support funding for digestive disease research.

By the end of the day, between us, we had met with staff in the offices of seventy-six legislators—forty-two House members and thirty-four Senators, representing twenty-seven states plus the District of Columbia—sharing stories in the hope of “putting a face” to the issues and personalizing the bills. At the end of the day, the groups—tired, but satisfied with a good day’s work and more than the 10,000 steps our fitness apps recommend—met to debrief and share notes so we and DDNC staff could most effectively follow up on the visits.

Access to Patient Care

The theme of the forum was “patient access to care.” The main priorities among all of us were the issues outlined below, but as each group made their visits, the stories varied, depending on the group and the audience. My group (New York), for example, was made up of a couple of nonprofit staff (like me), a gastroenterologist, and someone who has a rare gastrointestinal disorder that, when it developed, has changed their life. We each introduced ourselves and talked a little about the issues, but we always ended with the patient story. It was the most compelling, the story that would be remembered, and the reason we were all there.

As it is central to many in the home parenteral nutrition (HPN) community particularly, representatives from Oley and the American Society for Parenteral and Enteral Nutrition (ASPEN) were sure to mention the significant problems IV drug shortages are creating for our members. Other high priorities for Oley and ASPEN, in addition to the bills listed below, included the need for updates to the Center for Medicare and Medicaid Services (CMS) rules regarding coverage of HPN; and the current problems with pricing of HPN ingredients as they achieve FDA approval under FDA’s Unapproved Drugs initiative (more on this in an upcoming issue).

As a group, at this year’s Spring Public Policy Forum, we advocated specifically for the passage of the following bills:

• The Safe Step Act (S.2546/H.R.2279)
• Medical Nutrition Equity Act (H.R. 2501)
• Functional Gastrointestinal and Motility Disorders Research Enhancement Act of 2019 (H.R. 3396)
• Patients Access to Treatments Act
• Removing Barriers to Colorectal Screening Act (S.668/H.R.1570)
• Gluten in Medicine Disclosure Act of 2019 (S.3021/H.R.2074)

Watch for more details on these concerns and suggestions on how you can make your voice heard in coming issues of the newsletter or visit www.oley.org/legislation.

An Oley Member’s Experience

I have gone to DDNC for seven years and each year I go, I feel more invigorated and more passionate about advocating for the American digestive disease community. There are many issues being discussed and bills on the table in the House and Senate involving digestive diseases. Most people are very much unaware of them, but they will be affected by whether these bills are passed or not passed.

It is amazing to see that as Americans, we do have an opportunity to express our concerns to the people who can make things happen. It is one thing to be able to express ourselves on social media. It is another to make things happen because we actively participated in advocating for an important cause that will affect millions of people.

—Lynn Wolfson, Oley Ambassador
Especially in this time of COVID-19, when members of our community might be feeling more isolated than ever, we are excited to share with you a new mobile app from our partner Inspire. Currently available for iPhones and iPads, the app will provide a new way for members to engage with others in our online Oley-Inspire community.

The Oley-Inspire community is a great way to find social and emotional support from other home parenteral and/or enteral consumers and caregivers. The app is another way to access the Oley-Inspire community that was established several years ago and which members are accustomed to accessing from our website (see www.oley.org/Forum). You can view the same member posts on the app or the website, but the app has some features that are not available through the website.

Note that the same guidelines that apply online also apply to the app. See www.oley.org/Forum, if you have questions.

The app will allow you to connect with others in this online support group anywhere, anytime. Download the app today at www.inspire.com/app. Check it out and let us know what you think!
However, it has been slow going for mental health impacts to garner attention during medical visits. In recent years, these impacts are gaining significantly more attention, likely due to the rise of social media and patient advocacy efforts. This is slowly leading to a de-stigmatization toward talking about both physical and mental symptoms and how they're often related.

Multiple mental health challenges have been reported by patients and families managing HPEN. These problems include: anxiety; depression; difficulties with memory or planning; problems with intimacy and sexuality; stigma; food fears; problems with body image; and social relationships; sleep problems; and post-traumatic stress disorder (PTSD). Research statistics suggest anywhere from 10 percent to 80 percent of HPEN patients experience depression, while 41 percent have frequent anxiety. A study of seven hundred HPEN patients from fourteen countries found the biggest negative impacts on quality of life were related to sexual function, employment, and travel.

Each patient will have different impacts, and each impact may require different coping strategies. However, psychologists do know that some coping strategies are better than others depending on the situation faced. So coping needs to be adaptive and flexible to be effective.

**Problem-Focused Coping (PFC)**

The first main category of coping strategies is focused on solving a problem (hence our clever name). These strategies aim to reduce or remove the cause of stress in practical ways. Being practical is important because we can employ a problem-focused coping strategy that actually causes more stress than the original problem.

In the context of HPEN, a problem that may arise is needing your central line or feeding tube replaced. While generally not something a person wants to go through, this is a solvable problem. Calling your doctor, scheduling the appointment, arranging transportation to and from the clinic, and taking needed time off from work are all ways to solve this problem.

Experiencing insomnia is another solvable problem. We can evaluate our sleep habits—what psychologists call sleep hygiene—to see if we're doing things that actually perpetuate poor sleep. Let's say I'm having trouble falling asleep and I've gotten into the habit of taking naps in the afternoon. A solution to my problem would be to eliminate the naps. It may not fully solve my insomnia, but it's a step. If I still struggle, I can talk to my doctor, try an over-the-counter sleep aid for a short period of time, or learn some relaxation skills through a free phone application or YouTube video. All of these strategies help solve the problem in constructive ways. Properly applied, problem-focused coping can go a long way.

### Additional Resources

**Smartphone Applications**

- Buddhify: www.buddhify.com
- Calm: www.calm.com
- Breathe2Relax: www.psyberguide.org/apps/breathe2relax
- Mindfulness Coach: www.mobile.va.gov/app/mindfulness-coach
- Stop, Breathe, Think: www.stopbreathethink.com

**Websites**

- The Psych Show: www.youtube.com/ThePsychShow
- Stop, Breathe, Think: www.stopbreathethink.com

**Emotion-Focused Coping (EFC)**

Emotion-focused coping skills seek to reduce emotional responses to a situation, such as fear or anxiety, frustration, or embarrassment. Emotion-focused coping is helpful in any scenario, but especially in those where we cannot solve the problem. So, when looking at the scenario of the central line or feeding tube replacement, feeling fear or frustration would be two very normal emotions. Thoughts may drift to “why does this always happen to me?” or “I hate this stupid line/tube.” Spending too much time in this head space can certainly make life less enjoyable and it's time for emotion-focused coping. Strategies include talking to others or writing down what's upsetting, meditating, exercising, or evaluating your thinking and taking a different perspective.

### Which One Should I Use?

It's important to understand when to use emotion-focused or problem-focused coping. Many times, both are needed. Does the situation really have a solution? Yes—problem focused. Have I exhausted every option to try to solve this problem? Yes—emotion focused. Occasionally patients living with chronic illness overutilize problem-focused coping in an attempt to fix or cure, and their efforts turn into their biggest stressors. That's not to say we shouldn't try to fix our symptoms. However, there are limits to what medicine can do. Learning to switch gears to emotion-focused coping can reduce the stress of trying to solve unsolvable problems.

### Practical Tips

So what works? Thankfully there is a buffet of coping strategies available to help you deal with stress related to life with HPEN. I only have space to list the ones I feel are most important, but many mental health resources are available online and are listed in the box above.

1. **Evaluate Your Social Network:** Having a chronic illness is the best way to find out who your people are. Who have I told about my experiences? Who can I count on? Who hasn’t been the most helpful, and should I limit my interactions with that person? What online resources do I use, and, importantly, how do I feel after I use them?

2. **Am I Taking Basic Care of Myself:** Stop, look at your life, and think about what percentage of your time is spent on you. What do I do to de-stress? Does it work? If I don't exercise (walking counts) regularly, what keeps me from doing so? How’s my diet? How’s my sleep? Do I allow myself enough down-time each day?

3. **How’s My Self-Talk:** Our thoughts often become so automatic we don't even realize we're saying them, letting our internal critic take over and leaving us feeling irritable or sad or angry "for no real reason." When you're feeling a certain way you don't want to feel, ask yourself, what did I think just now? It may be hard at first to identify the thoughts. With practice, you can learn to turn off the brain's auto-
pilot. By doing this, you can then evaluate the thoughts and whether they’re useful or if they should be looked at differently.

4. Set Aside Structured Relaxation Time: Start with basic diaphragmatic breathing. It’s the only way we can directly control our heart rate, blood pressure, and muscle tension. Most adults are unrelaxed chest breathers. So, learning to breathe deeply from your abdomen may feel strange at first. With about two weeks of regular practice, you should start to see benefits. Best part, it’s 100 percent portable.

5. Up Your Relaxation Game: Meditation is all the rage and “basically fixes everything” (it doesn’t). With that being said, meditation can be a wonderful emotion-focused coping strategy. Not everyone can meditate, but most people can to some degree. It will be DIFFICULT to do in the beginning. Use an app (recommendations on page 6) to help guide you. Give yourself at least six weeks of regular practice—at least four days per week—to get good at it before you decide whether it’s your thing or not. After eight weeks, structural changes occur in the brain that translate to reduced stress in the body.

6. Write: Journaling, or what psychologists call “expressive writing,” has well-documented benefits. Writing for ten to fifteen minutes every day can reduce worry and help your brain process the day’s events. Writing is so good it’s an integral part of treatment of PTSD. Write as if no one will read it as this allows you to write authentically. Re-read what you’ve written and reflect on it for a few minutes when you’re done.

The best strategies to “cope” will include a mix of these methods, or others not mentioned here. Being able to shift between problem- and emotion-focused coping is exceptionally important. Please know nobody gets it right all of the time, not even us experts. The coping skills you choose to use should be improving your daily life with HPEN, not increasing your stress or causing new problems. If you find yourself struggling on your own, seeking help from a therapist or counselor is an excellent problem-focused coping strategy.

Addressing Consumer Fears Re: Supply of Ethanol Locks

As the supply dwindles of ethanol lock solutions that many patients are using to prevent catheter-related bloodstream infections, several of you have communicated your fears of how your “lifeline” will be affected. Home care company representatives, clinicians, and manufacturers have all expressed concern and are working behind the scenes to explore options to provide the best care for you. The FDA has opened an avenue for approving products via Emergency Use Authorizations. Several companies have applied for approval and we are keeping our fingers crossed that an appropriate option is approved. Clinicians have outlined the need for attention to this void in treatment and Oley staff has shared your fears and testimonials of years of infections halted once ethanol lock therapy was implemented. Your communication with us has allowed us to react quickly. Keeping our fingers crossed for a good outcome!
from home or miss a date with friends. And she makes sure she gets plenty of sleep, not always easy at age 25.

Amelse was diagnosed in 2012 with lupus, an autoimmune disease that makes her vulnerable to infections. She's since developed pulmonary arterial hypertension, a condition that requires intravenous therapy via a central line to her heart. Both illnesses place her at heightened risk for viral and bacterial illnesses. So, she has adapted as a matter of survival, taking to heart long-standing axioms on what constitutes good hygiene.

As the highly contagious new coronavirus continues its spread through the U.S., the general public could learn a thing or two from Amelse and the millions of other Americans with weakened immune systems who already live by rules of infection control. Whether it's people who had recent organ transplants, people undergoing chemotherapy or people with chronic diseases, America has a broad community of immunosuppressed residents who long ago adopted the lifestyle changes public officials now tout as a means of avoiding contagion: Wash your hands, and wash them often. Don't touch your face. Avoid that handshake. Keep your distance from people who cough and sneeze.

Amelse doesn't follow the advice perfectly — of course she touches her face sometimes. “You do these things unknowingly, so forcing yourself to break these habits can be challenging,” she said. But the incentive to keep getting better is there. “If you get a cold and you give me that same cold, you might get it for a week. I’ll get it for a month.”

Even with her dedication, COVID-19 is proving a daunting prospect to face. And she has a stake in Americans adopting these habits because, while the disease is relatively minor for many people who get it, it can be life-threatening for people with preexisting conditions.

Amelse works at a health literacy startup in Minneapolis that helps patients with complicated diseases learn about their illness. She knows a lot about health and how to prevent infection. Still, the threat of COVID-19 is unnerving, for her and her doctors.

With a virus so new, official guidance on what people at heightened risk should do to steer clear of COVID-19 is limited. But the Centers for Disease Control and Prevention recently said the virus seems to hit hardest in people 60 and older with underlying health concerns. There is also concern for younger people with limited immune systems or complex diseases.

Health officials are asking those at risk to stockpile two-week supplies of essential groceries and medicines in case they need to shelter at home; to avoid crowds and heavily trafficked areas; to defer nonessential travel; and to track what's going on in their community, so they know how strictly to follow this advice.

Infection control always follows a similar set of principles, said Dr. Jay Fishman, director of the Transplantation Infectious Disease and Compromised Host Program at Massachusetts General Hospital and a professor at Harvard Medical School. The most important things for people to do right now are the things he always recommends to his organ transplant and cancer patients. Again, think handwashing and avoiding spaces where sick people congregate.

Still, the recommendations aren’t one-size-fits-all. Some people are born with stronger immune systems, and immune deficits exist on a spectrum, said Fishman. How strict people need to be to prevent illness can vary depending on how susceptible they are.

Recommendations also need to take into account what people can and will do, he said. Children, for example, are among the greatest germ vectors of all time, but Fishman doesn't ask his patients with grandchildren to stay away from their young family members. “We did the transplant so you can see your grandchildren,” he might tell them.

Similarly, avoiding crowds and staying away from sick people is easy for some but can be all but impossible if you work in food service, for example. Find ways to avoid the risks and reduce them where possible.

Though there isn’t great research on how well transplant patients and others manage to prevent infection, Fishman said many of his patients don’t get sick any more frequently than the general population, despite their vulnerabilities. But when they do, the illnesses tend to last longer, be more severe, and put people at higher risk for additional infections. He counsels patients to be vigilant, but also to live their lives and not be ruled by fear.

Dr. Deborah Adey, a transplant nephrologist for UCSF Health, echoed Fishman, saying she likes to find ways to help her patients carry on with their lives. A patient recently asked if it was OK to fly to Salt Lake City, and she suggested they drive instead.

Gauging the risks can be tough. Amelse was relieved when a major health conference she was scheduled to attend recently in Florida was canceled at the last minute. She wasn’t sure it was safe to travel, but it also was unclear how to categorize an important work trip: Was this essential? Nonessential?

Adey conducts follow-up appointments via teleconferencing where possible, to keep her patients out of medical facilities. Hospitals are, by design, places for the sick, and people with compromised immune systems are generally advised to avoid them and the viruses and bacteria potentially inside.

That matches advice from officials in California and other states, asking people to stay out of emergency rooms unless absolutely necessary. They are asking people, when possible, to call ahead to their doctors and stay home unless an illness is serious.

And, similar to what public officials are advising the general population, Adey does not recommend that her patients wear face masks when out in public or even at the clinic. “The only people I would recommend is if they’ve got a lot of close contact with the general public, and they can’t afford to be off work.”

While much has been made of the hoarding sprees for face masks, the empty hand sanitizer shelves are equally frustrating for Amelse. Every 48 hours, she has to mix and administer drugs she places in an IV that goes into her heart. Everything must be sanitized, and she typically gets monthly shipments of antibacterial wipes and sanitizer. If suppliers run out, she’s worried she’ll have to go to a hospital to have the drugs administered—exactly where her doctors don’t want her to be.
Officials are desperately working on a vaccine for the coronavirus for use in as little as 12 to 18 months. But many vaccines are made from live viruses and can’t be given to some immunosuppressed people.

Given the risk COVID-19 poses for people with compromised immune systems, the government needs to stress how important it is for everyone to follow good hygiene protocols, said Fishman. “The worst thing we can do is downplay it.”

And for those just getting up to speed on preventing infections, Amelse has advice: “Viruses don’t pick and choose; they will latch on anywhere,” she said. Even if it’s not a serious illness for you, “there are people in your life that you can infect. You have the obligation and the responsibility to take care of your loved ones.”

Produced by Kaiser Health News (3/11/20), which publishes California Healthline, an editorially independent service of the California Health Care Foundation. Handwashing and catheter care posters follow this article.

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Handwashing and Hand Sanitizer Use

There are important differences between washing hands with soap and water and cleaning them with hand sanitizer. For example, alcohol-based hand sanitizers don’t kill ALL types of germs, such as a stomach bug called norovirus, some parasites, and Clostridium difficile, which causes severe diarrhea. Hand sanitizers also may not remove harmful chemicals, such as pesticides and heavy metals like lead. Handwashing reduces the amounts of all types of germs, pesticides, and metals on hands. Knowing when to clean your hands and which method to use will give you the best chance of preventing sickness.

When Should I Use?

**Soap and Water**
- Before, during, and after preparing food
- Before eating food
- Before and after caring for someone who is sick
- Before and after treating a cut or wound
- After using the bathroom, changing diapers, or cleaning up a child who has used the bathroom
- After blowing your nose, coughing, or sneezing
- After touching an animal, animal food or treats, animal cages, or animal waste
- After touching garbage
- If your hands are visibly dirty or greasy

**Alcohol-Based Hand Sanitizer**
- Before and after visiting a friend or a loved one in a hospital or nursing home, unless the person is sick with Clostridium difficile (if so, use soap and water to wash hands).
- If soap and water are not available, use an alcohol-based hand sanitizer that contains at least 60% alcohol, and wash with soap and water as soon as you can.
  - Do NOT use hand sanitizer if your hands are visibly dirty or greasy: for example, after gardening, playing outdoors, or after fishing or camping (unless a handwashing station is not available). Wash your hands with soap and water instead.

How Should I Use?

**Soap and Water**
- Wet your hands with clean running water (warm or cold) and apply soap.
- Lather your hands by rubbing them together with the soap.
- Scrub all surfaces of your hands, including the palms, backs, fingers, between your fingers, and under your nails. Keep scrubbing for 20 seconds. Need a timer? Hum the “Happy Birthday” song twice.
- Rinse your hands under clean, running water.
- Dry your hands using a clean towel or air dry them.

**Alcohol-Based Hand Sanitizer**
- Use an alcohol-based hand sanitizer that contains at least 60% alcohol. Supervise young children when they use hand sanitizer to prevent swallowing alcohol, especially in schools and childcare facilities.
  - Apply. Put enough product on hands to cover all surfaces.
  - Rub hands together, until hands feel dry. This should take around 20 seconds. Note: Do not rinse or wipe off the hand sanitizer before it’s dry; it may not work as well against germs.

Adapted from the Centers for Disease Control and Prevention’s (CDC’s) handwashing/hand sanitizer fact sheet. For more information or to get reproducible posters you can share, go to www.cdc.gov/handwashing.
STOP: Follow best practice – my line and my life depend on it!

CRUPULOUS hand hygiene –
- Between patients
- Immediately before and after caring for IV’s
- Immediately before putting gloves on
- Immediately after removing gloves

SEPTIC TECHNIQUE –
Always scrub the needless connector and the hub of the catheter using friction before every access
- Follow the instructions for use for the antiseptic used in your facility
- Do not reuse products for scrubbing or any connector that has been removed

EIN PRESERVATION –
My vascular access is my life line. Preserve my veins by:
- Keeping my line free from infection
- And free from other vascular access complications

ENSURE PATENCY –
Establish and ensure patency of every lumen of every line with:
- Each and every access use
- When administering medications
- When flushing unused lumens

*Do not use the lumen if you cannot flush each lumen without resistance or you do not have a free flowing blood return on every lumen!

KEEP ME FREE FROM INFECTIONS AND OTHER COMPLICATIONS.
I HAVE A LOT OF LIVING TO DO!

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Remembering Dr. Stanley Dudrick, “Father of TPN”

Here at Oley, we are still mourning the loss of Dr. Stanley J. Dudrick, who passed away peacefully in his home in January of this year, at the age of 84. Perhaps most widely known for his groundbreaking research on total parenteral nutrition (TPN), Dr. Dudrick was a valued member of Oley, taking the time to attend and speak at multiple conferences. Oley recognized his contributions with an award in 2017.

Dr. Dudrick first began his research on intravenous (IV) nutrition in the 1960s, after losing three patients post-operatively, and realizing it was due to malnutrition. He famously tested his theory of complete IV nutrition on a litter of beagle puppies, successfully feeding them entirely by vein from six weeks of age into adulthood. In 1967, after successfully treating six adult patients with TPN, Dr. Dudrick was presented with an opportunity to try to help a newborn baby with congenital small bowel atresia, who was unable to take in nutrients by mouth. Dr. Dudrick and a team at Children’s Hospital of Pennsylvania (CHOP) worked tirelessly to save the baby girl, named Kelleen. After six weeks of TPN, baby Kelleen’s weight was nearly double what it was at birth, and her growth and development continued unhindered for the first year of her life.

“Dr. Dudrick questioned conventional wisdom, and inspired an odyssey of discovery that fundamentally changed our understanding of the nutritional needs of critically ill patients,” said Department of Surgery chair at Yale, Dr. Nita Ahuja. “His story speaks to [the] power of curiosity to change the world.”

In 1975, continuing to use that curiosity and goodwill, Dr. Dudrick founded the American Society for Parenteral and Enteral Nutrition (ASPEN) and became its first president. Today, ASPEN has over 6,500 members. ASPEN continues to support research in the field of nutrition support and is a leader in establishing best practices and guidelines in relation to HPEN. It is an invaluable resource to the Oley Foundation.

Current ASPEN President Dr. Lingtak-Neander Chain says, “[Dr. Dudrick’s] legacy goes far beyond his pioneering research.” After publishing his research on TPN, Dr. Dudrick went on to write multiple articles and textbooks, mentor many in the next generation of TPN providers, and chair surgical departments at four different institutions. During his more than forty-year career, Dr. Dudrick received over one hundred honors worldwide, including ASPEN’s first Lifetime Achievement Award in 2017, and the American Surgical Association’s first Flance-Karl Award, given to American surgeons who make significant contributions to basic laboratory research with clinical surgery applications.

To the Oley Foundation and its members, Dr. Dudrick’s achievements are nothing short of life-saving, he will be remembered for his devotion to his work, to his colleagues, and, most of all, to those who are alive today because of TPN. “This man,” says Oley member Pam W., “who developed the technology that saved Ally’s [Pam’s daughter’s] life, was such a humble, sweet man. When I thanked him for his work that saved Ally’s life, he replied that these kids are the real heroes. We are so grateful to the Oley Foundation for providing the conference that allowed us to meet him in person.” Pam was one of several Oley members who added to an article Oley was invited to submit to an issue of the *Journal of Parenteral and Enteral Nutrition* devoted to Dr. Dudrick.

In a 2006 interview, Dr. Dudrick stated: “I hope that I would be remembered as somebody who truly, greatly appreciates the privilege of having spent a wonderful life with wonderful parents, family, teachers, mentors, colleagues, residents, fellows, students, staff, friends, and patients, who have contributed so much to enrich my life and to allow me to feel that I might have achieved some of my own goals and aspirations and whatever the purpose or purposes were of my creator.” This rings true in the hearts and minds of the many whose lives Dr. Dudrick touched.
In this time of the pandemic coronavirus, it is essential for people to maintain social distancing and stay in place at home as the Centers for Disease Control (CDC) recommends, particularly those with chronic health conditions. And many of our chronically ill patients may need more than telephone contact about their conditions. Specifically, home parenteral nutrition (HPN) infusion consumers may still need to interact visually—for example, to show their IV lines to their healthcare providers. While our research was focused on HPN consumers, we know that home enteral nutrition (HEN) patients, too, may need to connect with their healthcare providers visually to resolve an issue. If so, one method for doing this is to connect using telemedicine.

Telemedicine is the use of videoconferencing to enable a healthcare provider to interact with patients who are at home in real-time. As restrictions on activities and closures of facilities increase on a nearly daily basis, telemedicine may be the best way to provide continuity of care, urgent care, social support, or meet other needs while limiting broader exposure of patients and healthcare providers to the COVID-19 pathogen.

Uses of Telemedicine

Telemedicine can be used in many ways, but there are two general ways it can be best leveraged during this unprecedented outbreak. First, it can be employed to screen HPN patients who have concerns that they are exhibiting symptoms of COVID-19 or think they may have been exposed. Clinicians can quickly connect with a patient in his or her home; they can see and talk to each other, and the clinician can evaluate symptoms and recommend next steps.

The second way telemedicine can be used is for providers to consult with their current HPN patients or non-coronavirus patients who have routine appointments scheduled or need some other clinical assistance, thereby limiting their broader exposure to others at this time and reducing clinic or hospital patient traffic. It is important to note that while the telemedicine video itself may not be needed to assess COVID-19 or manage other clinical needs, video is required at this time for telehealth reimbursement purposes per the Centers for Medicare and Medicaid Services (CMS), state Medicaid, and most private payers. Audio-only consults over the telephone are not reimbursed at this time by the insurers.

Expanding Telemedicine in Time of Need

During this unusual time, many of the federal agencies and states are making special policy accommodations to allow for more telemedicine to be provided to both coronavirus patients and non-coronavirus patients. For example, CMS has temporarily eliminated the geographic restrictions for telehealth so patients will be covered by CMS regardless of whether they are in rural or urban areas. In addition, reimbursement for these services will be covered by CMS if the originating site is the patient’s home—it doesn’t have to be from one clinical setting to another at this time. (For billing purposes, the process for telehealth consultations is the same as for an in-person visit except “place of service” is coded a 2.)

In addition to CMS, the Office of Civil Rights (OCR) within Health and Human Services (HHS) has announced it will waive any potential penalties to providers who use non-HIPAA compliant video applications to provide telehealth services to patients. This means that some common video programs like Facetime, Skype, Google Hangouts, and others can now be used for providing telehealth during this crisis. The guidance indicates that telehealth services that are provided in good faith and with all other available best practices will not be penalized. However, providers should notify patients of the potential for security risk if one of these non-healthcare video applications is utilized. This policy is effective whether telehealth is used for coronavirus patients or not.

Most of these platforms are simple to use with just a little practice. Often, they only require a patient’s email address, telephone number, or username to connect directly to the patient on their home computer, iPad, or even Smartphone. With several of the cloud-based web conferencing systems such as Zoom or GoToMeeting, a date and time is selected for the appointment and a link is emailed to the patient. At the time of the connection, the patient simply clicks the link.

For other apps, like Facetime, the process may be even simpler. If the provider and patient both have an Apple device, a provider can simply open the Facetime app, select the patient’s contact phone number, and tap it. The call will instantly be made to the patient’s device. Clinicians and their staff will just need to spend a little time to determine what platform might already be available in their organizations and whether it will work across devices and brands, or if a combination of platforms may be needed.

Further, on March 18, 2020, it was reported that HHS will permit all medical care providers to practice across state lines, regardless of their state license, in order to treat more coronavirus patients. No other details have been provided as of press time and it is unclear how...
state licensing boards will implement this policy. Providers are strongly encouraged to check with their state boards before providing telehealth across state lines until more detail is provided in the coming days. However, with this and the other unprecedented accommodations that have already been made, it is possible that HPN patients may be able to access needed services via telemedicine no matter where they live.

Navigating the Logistics

There are multiple models for incorporating telemedicine visits into the clinical setting and workflow. One common model, particularly for lower volume, is for providers to conduct telehealth visits in-between their regular in-person patients or when they have patient no-shows. These are sometimes independently initiated by the provider and conducted right from his or her office, thus freeing up exam rooms. For higher volume, this model can also be used, or a block of time can be set aside in which patients are scheduled. In this model, more coordination with the office staff is needed to schedule the patients and get them connected for their virtual visits to maximize clinician efficiency.

In any scenario, while some of the technical HIPAA requirements have been modified during the COVID-19 pandemic, practitioners should still observe other privacy best practices, such as having a private room from which to conduct the telemedicine consult; informing the patient of the potential for reduced security if using a consumer-level video application; and ensuring that all security settings on the app are maximized. In addition, while not always possible on all devices, it is suggested that a high quality or high definition (HD) camera be used; and, if using a desktop or laptop computer, that an internet cable be used instead of Wi-Fi. These safeguards will help ensure the best audio/visual experience for HPN patients and their providers.

Benefits of Connecting

The other important way, in this time of social distancing, that telehealth connections have been shown to be significant are in connecting groups. In our research, we have multiple professionals meet with a patient and their family. Most often these professionals report how they have better understanding of the complete plan for the patient across all the providers. Also, individual patients can be assessed privately and the family members separately, to obtain “two sides” to the symptom story.

Our other research outcomes are being able to “see” depressed signs and symptoms, and even judging suicide ideology. Lastly, we have published other findings on our successes with groups of patients (especially teens and young adults) in discussion groups over telehealth. These populations have enjoyed using their own and loaned iPads to “Zoom” in to their healthcare providers. This allows providers to give out the correct information needed for these young people to adjust to and correctly manage their medical regimens. In our research across the age range of HPN patients and their families, we see great benefit from groups coming together.

In our studies with patients meeting using iPads’ audio-visual capabilities, we use guidelines for social media and health safety: encouraging patients to NOT share any health information and to not meet in person anyone they have only met on the internet. We also encourage that no medical advice be given. The evaluations of such group sessions have consistently been that it is helpful to meet by distance others who have similar situations. Medical centers typically have encrypted and fire-wall protected telehealth devises or connections; we caution against using commercial devises so that patients’ privacy is protected.

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**Scripts for Controlled-Substances During COVID-19**

Shawna Wright, PhD, KU Center for Telemedicine & Telehealth, University of Kansas School of Medicine

Recently the Drug Enforcement Agency (DEA) published guidance relating to the COVID-19 public health emergency, which includes an exemption to the federal Ryan Haight Act’s requirement to conduct an in-person exam before prescribing controlled substances via telemedicine. In response to the public health emergency, DEA-registered practitioners may now issue prescriptions for all Schedule II–V controlled substances to patients without first conducting an in-person medical evaluation, providing (1) the prescription is issued for a legitimate medical purpose by a practitioner acting in the usual course of his/her professional practice; (2) the telemedicine communication is conducted using an audio-visual, real-time, two-way interactive communication system; and (3) the practitioner is acting in accordance with applicable federal and state law. More details at www.deadiversion.usdoj.gov/coronavirus.html. Editor’s note: We have heard of delays with scripts due to skeletal staffing in some offices.
Thank You Corporate Partners!

Please join Oley in thanking the companies that support us year round. Learn more about our most recent corporate contributors below. For a complete list of corporate partners go to www.oley.org/PartnerShowcase.

Takeda
Takeda is a global, values-based, R&D-driven biopharmaceutical leader headquartered in Japan, committed to bringing better health and a brighter future to patients by translating science into highly innovative medicines. Visit www.takeda.com.

ThriveRx
ThriveRx is proud to be a Silver Circle Partner of the Oley Foundation. The company 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 thrivexrx.diplomat.is to learn more about its short bowel and iThrive programs.

Cardinal Health, Inc.
Cardinal Health, Inc. is a global, integrated healthcare services and products company, providing customized solutions for hospitals, healthcare systems, pharmacies, ambulatory surgery centers, clinical laboratories, and physicians worldwide. The company provides clinically proven medical products and pharmaceuticals and cost-effective solutions that enhance supply chain efficiency from hospital to home.

Fresenius Kabi
Fresenius Kabi is a leading global healthcare company that focuses on pharmaceuticals and medical devices used to care for critically and chronically ill patients inside and outside the hospital. Fresenius Kabi products include intravenous specialty and generic medicines, transfusion technologies, infusion therapies, clinical nutrition, and related medical devices.

Kate Farms
Kate Farms is a medical nutrition company offering a high standard of enteral formulas that, it says, are “well tolerated, made with organic ingredients without allergens commonly used in other conventional formulas, and broadly eligible to be covered by insurance.” The company says its products offer “improved tolerance, quality of ingredients, and delicious taste.”

Zealand Pharma
Zealand Pharma is changing patients’ lives with innovative peptide therapeutics. Patients inspire the company to provide the best possible solutions for gastrointestinal and metabolic disorders. The company is building upon twenty years of expertise in developing treatments for patients with short bowel syndrome.

Applied Medical Technology, Inc. (AMT)
AMT is a global leader and manufacturer of enteral feeding devices, cecostomy devices, and accessories. Its products include: MiniONE® family of low-profile g-tubes, traditional-length g-tubes featuring its exclusive Capsule Technology, G-JET® low-profile gastric-jejunal feeding tube, MiniACE® low-profile antegrade enema button, CINCH® tube securement device, and AMT Bridle™ nasal tube retaining system.

Cook Medical
Since 1963 Cook Medical has worked closely with physicians to develop minimally invasive technologies. Today the company is combining medical devices, biologic materials, and cellular therapies to help the world’s healthcare systems deliver better outcomes more efficiently. Find out more at www.cookmedical.com, and follow on Twitter, Facebook, and LinkedIn.

MOOG Medical
Infinity enteral feeding pumps by Moog are 100 percent mobile enteral feeding pumps, providing patients of all ages the ability to live life more fully. The company’s industry-leading clinical and customer support teams are available to assist customers and patients twenty-four hours a day, seven days per week.

VectivBio
VectivBio AG is a global biotechnology company committed to making a difference in the lives of patients suffering from serious rare conditions. The company is assembling a pipeline in rare diseases, with a program aimed at patients living with short bowel syndrome.

Published in Good Company

The Oley Foundation was recently invited to contribute a chapter focused on the value of support groups to a special edition of Gastroenterology Clinics devoted to intestinal failure (see www.tinyurl.com/OleySupportGroups). The volume was published in December 2019 by Elsevier. Julie Andolina, who has been working at the Oley Foundation as an intern and who has been on and off home enteral and/or parenteral nutrition all of her life, wrote the article drawing from her own experience. Joan Bishop, Oley Executive Director, and Lisa Crosby Metzger, editor of the LifelineLetter, supported the effort with added insights and information about Oley programs.

Edited by Alan Buchman, MD, the list of topics and the contributors is impressive. The volume includes chapters on subjects such as initial evaluation of the patient with intestinal failure (C. Harris and J. Scolapio), preparing the patient for home parenteral nutrition (N. Evans Stoner, P. Schiavone, B. Kinosian, O. Pickett-Blakely, V. Amoroso, R. Coughlin, Z. Xue, and C. Compher), etiology of pediatric intestinal failure (E. Mezoff, C. Cole, and V. Cohran), intestinal adaptation in children (R. Venick), management of chronic intestinal pseudo-obstruction (L. Pironi and A. Simona Sasdelli), weaning from parenteral nutrition (A. Ukleja), hepatobiliary complications (A. Van Gossum and P. Demetter), nontransplant surgery (R. Colletta, A. Morabito, and K. Iyer), indications of intestinal transplant (A. Kahn, K. Tulla, and I. Tzvetanov), artificial intestines for the treatment of short bowel syndrome (M. Kovler and D. Hackam), and engineered intestine (D. Levin). We are pleased to have been able to contribute something representing the consumer viewpoint.

All of the articles mentioned above are available by subscription or individually, for a fee, at www.gastro.theclinics.com (see December 2019 issue, volume 48, number 4).
The Lasting Legacy of the “Oley” Oldenburg Family

The Oley Foundation recently received a generous gift from the estate of Kay Oldenburg, the wife of our co-founder, Clarence “Oley” Oldenburg.

Kay and Clarence’s daughter, Cindy Macko, writes, “I want to thank you for all the work you do to keep the [Oley] Foundation going. At its start we never thought it would still be going 35+ years later. But thanks to the foundation and Dr. Howard so many more people are getting the help and chance for a longer life.” She adds, “They told us in 1975 when my Dad had his surgery he was not going to survive. Thanks to Dr. Howard we had him around for another 32 years!”

J. William “Bill” Oldenburg, who donated Oley’s start-up funds past away in 2019, not long after his sister-in-law Kay.

We are grateful for all the support and inspiration we’ve received from the Oldenburg family over the years. Truly their gifts have saved and enriched thousands of lives.


Notable Individual Gifts

Among the contributions we receive, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. We are grateful for the following gifts received from January 25 to March 13, 2020.

Tributes: In honor of Hadar Birger-Bray; Jackie Dam; Joy McVey Hugick; Aidan Koncious; Jonathan Miller; Sam O’Connor; Aiden Raffe, 1 year off HPN

Memorials: In memory of Jacques Lamar Alexander; Jackie Dietrich; Stanley Dudrick, MD; Clarence (“Oley”) and Kay Oldenburg; Gregorio Tongol

Fund-raisers: AmazonSmile, Facebook

Matching Gifts: American Family Insurance

Correction: We regret that in the annual donor list featured in the January/February edition of the LifelineLetter, we misspelled a donor’s name. The correct entry for the Kudan family should be as follows: “Nancy, Peter, Jerry, and Alan Kudan, in memory of Shirley Klein, beloved mother, mother-in-law and grandmother who passed away 20 years ago after having been on HPN for 20 years.” Our apologies to the Kudan family, and our thanks for their continued support of the Oley Foundation.

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

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 strong commitment.

TITANIUM LEVEL PARTNER ($150,000+)
Takeda Pharmaceutical

GOLD MEDALLION PARTNER ($50,000–$69,999)
Option Care

SILVER CIRCLE PARTNERS ($30,000–$49,999)
Coram / CVS Specialty Infusion Services
Nutrishare, Inc.
ThriveRx

BRONZE STAR PARTNERS ($20,000–$29,999)
Avanos
Baxter International Inc.
Cardinal Health, Inc.
Fresenius Kabi USA
Kate Farms

BENEFACCTOR LEVEL PARTNERS ($10,000–$19,999)
BioScrip Infusion Services
Nestlé Health Science
Optum Infusion Pharmacy
Real Food Blends
Zealand Pharma

PATRON LEVEL PARTNERS ($5,000–$9,999)
Applied Medical Technology, Inc.
Cook Medical
MOOG Medical
Soleo Health
2020 Oley Calendar

Because of the uncertainty of gatherings at press time, we are postponing the Oley Calendar segment in this issue of the newsletter.

Oley Is Here for You

We recognize what a challenging time this is for everyone. You are continually on our mind—from the nutrition support consumers who are especially at risk with the coronavirus, to those who care for these consumers, to the healthcare professionals who are being called on to help in unimaginable ways.

The Oley staff is dedicated to this community. We are working from home and respecting the need for social distancing. We will do our best to help keep you safe and sane. Recognizing that other organizations are better equipped to provide you with timely updates on the coronavirus, we will try to share, and not duplicate, those efforts.

Keep an eye on our website (www.oley.org) for more timely information. We will continue to focus on what we always focus on—providing you with the best information we can from experts in the field of home parenteral and enteral nutrition and related fields; encouraging peer-to-peer support, through the internet and social media efforts, phone, webinars, etc.; and being available if and when you need us. Although staff is not in the office, we check our phone and email messages regularly. Please let us know how you and your families are doing. We want to hear from you.

In terms of future meetings, the regional conference in Charlotte has been rescheduled for November 14. Plans for the Oley 2020 Conference have been halted and negotiations are under way with the Marriott to identify alternatives to the planned June dates. We are monitoring the situation with COVID-19 carefully and continuously. The health and safety of our members is our highest priority. Again, stay tuned to www.oley.org!

You are in our thoughts. If there is some way we can help in these challenging times, please let us know. Reach out to us individually (see staff email addresses on page 2) or at oleyfoundation@gmail.com, or by leaving a message at 518-262-5079.