Considerations When Choosing a Home Care Agency

Steven Plogsted, PharmD, BCSNP, CNSC

Your life has changed, and now you need help from a home care agency to provide you with needed services. Initially, a hospital discharge planner or your clinician may set you up with a home care agency. You do, however, have the right to be involved in the decision or to later switch to another home care agency, as long as the company you choose accepts your insurance. What should you consider or what questions do you need answered to determine if a new home care agency will meet your needs?

Quality and Clinical Expertise

Your first consideration should be quality. Before you decide on an agency, try to ask others about the agency's reputation. This may be a difficult task because home care agencies can't give you a list of their customers due to confidentiality laws. You may know other consumers who require the same level of care that you do or you can discuss your options with the doctor who prescribes your home parenteral and/or enteral nutrition (HPEN). Many of them will be familiar with different companies and any problems associated with them.

There are also questions you can ask that will indicate the agency's level of quality and clinical expertise:
- What level of education and training do the clinicians possess?
- Specialty certifications in nutrition support are available for pharmacists, nurses, dietitians, and physicians. These certifications require at least a minimum level of knowledge in clinical nutrition. Although not a requirement to practice, the certification does demonstrate a higher level of commitment to the consumer by the agency (see chart on page 2).

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Conference Benefits

Peter S. Lee

If I was someone who had never attended an Oley conference (as I was last year), the biggest question I would have for a conference veteran would be, “Was it worth the trip?” The 2011 conference was being held seven hundred miles away and would require almost twelve hours of driving one-way. Just like with everyone else, money is a concern, as well as getting the time off of work, etc.

Today, if anyone asked me if it was worth the trip, I would answer, “Yes, it was worth the trip, and here’s why.” Alone, any one of the following things would have made it worth the trip.

Understanding

By attending the conference, my wife Donna was able to spend several days with people who TRULY understand the challenges in her life that are a consequence of enteral (EN) feeding. Those who surround
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• Does the agency have a consultant physician? Your own physician may have a different level of knowledge about clinical nutrition issues and it is helpful if the agency has an expert who will work with your physician to provide the best outcomes for you.
• Does the agency employ a nursing staff or does it contract with a nursing service? Do they train the contracted employees? Do the nurses have experience with line care? Are nurses available on an urgent basis?
• Does the agency have a social worker available? A social worker can be invaluable in advising you on insurance issues, disability, and, and so on.
• Does the agency have a consumer advocate available, or can they direct you to a local support group to help you through issues that you need help with?
• Is the agency active with the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and/or Oley? Is the agency up-to-date on the latest research and protocols (particularly in relation to parenteral nutrition)? Does the agency have experience with your disease state? These questions can be more or less important, depending on your physicians’ level of experience with HPEN and/or your disease state.

Most agencies are available twenty-four hours a day, seven days a week, to help with any issues that arise, but you shouldn't take that for granted. Ask about their availability.

Insurance
Another important consideration in choosing a home care company is determining what agencies your insurance carrier has in its network. Insurance carriers usually develop contractual arrangements with several agencies in order to keep their costs down; these agencies will be considered “in network.”

What if the new home care agency you'd like to have serve you is not in your insurance carrier's network? It doesn't entirely rule them out. You can contact the agency's insurance representative and ask them to contact your insurance carrier to see if they can work out a contract. If you are insured through an employer, the employer's human resources representative may also be able to help you in discussions with the insurance carrier. If the home care agency you choose is not in the insurance carrier's network, make sure you understand your financial responsibility; there should be no surprises.

You should make a habit of contacting your insurance carrier periodically to make sure your home care agency is still in its network—or will be in the network during the next benefit year—as sometimes the contracts change. Often your home care agency will automatically check this for you. A good home care agency is proficient at two-way communication, and doesn't rely on the consumer to make all of the calls.

Likewise, if you change insurance companies (or if your employer requires you to change insurance companies), check to make sure your home care agency is in the new insurance company’s network. You don't want to discover when you are down to your last bag of parenteral nutrition (PN) or last can of formula that your new insurance company doesn't have your agency in its network. Ask your insurance company if they routinely notify consumers of changes to their coverage.

Geography
When evaluating a new agency, make sure it serves the geographical area where you live. Some agencies have a limited service area and may not be able to deliver or ship outside of that area. Some agencies will not do business across state borders (more on this later).

Consider your plans and habits. Do you want to be able to travel? If so, how often and how extensively? Home care agencies are often

Choosing Home Care, cont. pg. 10

Certifications
CNSC = Certified Nutrition Support Clinician
CNSP = Certified Nutrition Support Physician
CNSN = Certified Nutrition Support Nurse
CNSD = Certified Nutrition Support Dietitian

The National Board of Nutrition Support Certification, Inc. (NBNSC) certifies proficiency for physicians, nurses, pharmacists, physician assistants, and dietitians. In 2008, certification exams for each discipline (i.e., physician, nurse, dietitian) were replaced by a single exam that recognizes nutrition support as a multi-disciplinary endeavor and the CNSC was established. It encourages attainment of a credential based on job performance and the development of cross-coverage skills. More information at www.nutritioncare.org/NBNSC.
Tube Talk

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

Backpack for Small Child

My son is on G-tube [or enteral] nutrition. In addition to night feeds, we often need to pump feed him during the daytime. Getting an active toddler to wear the backpack can be challenging. We were using the backpack supplied by our insurance carrier. While it worked, because my child is so very small, it had many shortcomings.

After much experimentation, I have found something that works really well for us. I purchased a child’s CamelBak MiniMule hydration backpack. These are made for holding water during sports, while biking, etc. With very little modification (removal of the bladder), I was able to make this accommodate a Zevex pump and feed bag.

Because the clip goes across his chest instead of his waist, it is much more secure for an active tot. Also, it fits better because the CamelBak is narrower and more contoured to his little body.

Again, I am sure the backpacks work fine for older/larger children, but this CamelBak is perfect for my small child.

One other lesson we learned the hard way: with the backpack, we were routing the feed tube to his G-tube from the bottom of the backpack, which is how I thought it was designed. We routed the tube from the bottom of the backpack to the bottom of his shirt, then up to the G-tube. It was not very noticeable. However, a running child can easily catch the tube on playground equipment, household furniture, etc. (Yes, we did this and completely pulled out the button!) With the CamelBak, the tube comes out of the top of the pack, then I run it into his shirt at the neck, and down to his button. There is much less opportunity for the tube to be snagged!

—Michele Horton dinoposs@hotmail.com

Editor’s note: We have also heard from adults who have adapted CamelBaks to accommodate their pumps and bags. There’s a discussion on the Oley forum about this, at www.inspire.com/kkoepp/ejournal/tube-feeding-and-style/
Second Feeding Tube Awareness Week a Great Success!

Traci Nagy

Feeding Tube Awareness Week is growing and taking hold! The goal of this awareness week, which was held for the second time in early February, is to raise awareness of tube feeding as a vital medical intervention that saves lives. Awareness promotes understanding, both of the challenges tube-feeding families face and the medical conditions that make tube feeding necessary.

As with last year, tube feeders, parents, and caregivers were encouraged to share parts of their day-to-day lives and discuss topics such as: why awareness is important; how family and friends’ attitudes towards tube feeding have changed with greater awareness; and what the medical community needs to better understand about tube feeding.

This year, the Feeding Tube Awareness Foundation formed a stronger partnership with the Oley Foundation. There was also greater participation from other organizations, including the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), G-PACT, the American Partnership for Eosinophilic Disorders (APFED), United Ostomy Associations of America, MitoAction, the Oregon Medical Association, Complex Child, Mommies of Miracles, and Tubie Friends.

There was also greater participation from corporations, which, for example, posted announcements on their Web sites and in their newsletters and distributed awareness week buttons to employees. We'd like to thank these corporations, including Kimberly-Clark, Shield HealthCare, Applied Medical Technology, Neocate, ThriveRx, and Home Solutions Infusion Therapy, for their help in promoting awareness.

The most important piece of this is that Feeding Tube Awareness Week continues to make tube feeders, parents, and caregivers feel less alone. There are hundreds of thousands of tube feeders in the United States. Our voices won’t be heard unless we talk about it.

Activity Highlights:

• Several families appeared in their local news media on TV and in newspapers. (Oley has posted links at www.oley.org/Tube_Feeding_Awareness_2012.htm.)
• 2,293 people RSVP’d to the Facebook event page—a 55 percent increase from last year.
• According to Facebook, the Feeding Tube Awareness page (the hub for Awareness Week activities) content reached more than 34,000 people through people sharing content from the page. This doesn’t even include posts made directly by participants!
• 222 families shared their photos for the Awareness Week video (www.feedingtubeawareness.org/raising-awareness.html), which was seen by thousands on One True Media and on Facebook.
• Several parents and children gave presentations to school classes about tube feeding. It proved to be educational and a lot of fun. Teachers and schools were very accommodating to requests to honor the week.
• Dozens created their own Awareness Week videos to share. Mark your calendars! In 2013, Feeding Tube Awareness Week will be February 3–9.

A Little Data on HomePN Can Go a Long Way

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is celebrating the one-year anniversary of Sustain™, LLC, its national patient registry for nutrition care—and we need your doctors, nurses, dietitians, and homecare companies to participate!

“Sustain is well on its way to becoming a valuable resource that registry participants and healthcare providers can rely on for information about the annual utilization of HPN [home parenteral nutrition],” says Marion Winkler, PhD, RD, LDN, CNSC. “This data will help organizations make better-informed treatment decisions, support the appropriate use of nutrition support therapy, and help translate results into improved outcomes for patient care.” Dr. Winkler, a Surgical Nutrition Specialist at Rhode Island Hospital and Associate Professor of Surgery at Alpert Medical School of Brown University, co-chairs the Scientific Council of Sustain and is an Oley Trustee.

Data on more than 300 consumers using HPN have been entered into Sustain to date and thirty-seven large medical centers, hospitals, and home infusion agencies have enrolled in the registry, with ten entering data. A.S.P.E.N. urges all U.S.-based clinicians who discharge, manage, or care for HPN consumers to participate in Sustain.

Clinicians enter the data through a secure, online portal; identifiable information is completely confidential and names are not entered into the registry. Sustain participants can benchmark their consumer data against the national aggregate, pose research questions, publish clinical research based on registry findings, and more.

“Sustain is the innovative data collection system that nutrition support providers seek,” Dr. Winkler continues. “This data will ultimately help HPN consumers realize better treatment outcomes. It’s a great opportunity for clinicians and consumers alike—and we encourage you to ask your doctors and healthcare professionals to get involved.”

To learn more, visit www.nutritioncare.org/sustain or contact KatyH@aspen.nutr.org, (301) 920-9133.
Nutrition and You  

Tales from Our Clients: Natural Stool Bulkers

Yes, it is true—much of what we learn is actually from our patients. If we listen carefully and we start to hear the same things over and over again, then we know there may be some truth to what we’ve heard. Patients do not lie.

So, what have we heard from our patients? Here are some of the things that you all have said “bulk things up.” They may or may not have scientific validity, but we have heard them a lot.

1. **Soft pretzels**—those big, soft pretzels that you often find at baseball games and summer fairs. Many of you have reported that they work better than your antidiarrheal medications! There may be some truth to this. These pretzels are high in complex carbohydrates, which tend to “bulk things up.” It is worth a try, and they are rather tasty.

2. **Rice**—yes, plain white rice is a good standby. This is a little tactic that many of you have used over the years and swear by. Again, this makes some sense, since it is a complex carbohydrate and may slow down motility and absorb water.

3. **Marshmallows**—well, we have heard this a lot. Does it work? Perhaps! Is there any scientific reason for this? We cannot think of any reason why this should work, but if it does work for you, stay with it! Just make certain you don’t include a lot of gooey chocolate with those marshmallows.

4. **Green beans**—plain boiled or steamed green beans have been reported to slow things down. There is some soluble fiber in green beans, so it may work for many of you. But if it makes your diarrhea worse, stop the green beans!

5. **Bananas**—bananas are another mainstay for those with diarrhea. Some of our consumers eat bananas every day because they swear they slow them down. This makes some sense as bananas are high in soluble fiber, and soluble fibers do absorb water.

6. **Oatmeal**—Now, this is one of those foods that can work both ways. It might bulk you up, or if you are constipated it might loosen things up. Again, this makes some sense because oatmeal is high in soluble fiber and tends to absorb water.

The one thing we do know is that each HPEN consumer is very special. Rarely do we have two clients who react exactly the same to any given food or treatment. So give these things a try—one of them may help! Please send us your ideas (c/o Lisa Metzger, Oley, 214 Hun Memorial, MC28, Albany, NY 12208, or metzgel@mail.amc.edu). We’d love to hear what works for you.

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“I’ve been on tpn, oxygen and in a wheelchair for many years due to my chronic illness. My idea of traveling has been watching the Travel Channels on T.V. Since starting with ThriveRx, I have more options. When I need to travel, ThriveRx is there to help. Thank you for letting me THRIVE!” - Linda Z

**ThriveRx Travel Program**

Many people on enteral and/or parenteral nutritional support travel frequently. ThriveRx has put together some tips for these individuals and their families to make traveling easier. If you are taking a Caribbean cruise, flying to Hawaii, or driving across the country, ThriveRx will help to make your travelling experience stress free!

For more information on our Tools to Thrive, visit our website at [www.thriverx.net](http://www.thriverx.net)

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

Conference Benefits, from pg. 1

her at home love and support her, but it is entirely different to be around people who know from experience what you go through on a daily basis.

For those days, Donna didn't have to put on a happy face and pretend her condition didn't exist. The empathy and compassion shown both by the attendees and the staff was a lesson straight out of the scriptures. The people who worked the conference were clearly there out of compassion and a desire to support and assist the attendees.

Education

The sessions we attended taught us things we did not know about tube feeding and other related topics. The question-and-answer portion of each session was invaluable. Many times it was a springboard to other topics, other sessions, and friendships.

Problem Solving

By a stroke of good fortune, the company that makes Donna's EN pump was one of the exhibitors at the conference. Donna had had problems trying to get the pump to work when she put it in the carrying bag they had graciously supplied to her. Calls to their customer support did not get us past the problem as we could not figure out from their description on the phone what needed to be done (though they tried very hard to help us).

In five minutes, the company reps at the conference demonstrated what we needed to do to make the system work in the carrying bag. As a consequence, Donna is no longer confined by having to drag around her IV pole. She can use her pump in its small carrying bag to move around the house, go outside, go places with others, etc.

Friendships

We made some wonderful new friends at the conference. Not people to commiserate with or to bemoan our lot with...I saw none of that. We made some wonderful new friends at the conference. Not people to commiserate with or to bemoan our lot with...I saw none of that. We made some wonderful new friends at the conference. Not people to commiserate with or to bemoan our lot with...I saw none of that.

Definitely Worth the Trip

By the time the conference had ended, I was amazed at the number of times over those few days I had said to myself that “this thing” or “that person” alone would have made the trip worthwhile. I am so grateful we had the opportunity to attend.
Auction Items Needed

The silent auction held at the annual conference has raised thousands of dollars for Oley, helping to keep programs free for you! Your help in gathering items (handmade quilts and scarves, collectibles, DVDs, books, photos, paintings, gift certificates, time-share units, frequent flyer miles, concert or sporting event tickets, etc.) has been key. We’ve also raffled off some larger “big hit” items that were solicited by Oley members (such as iPods and laptops), generating hundreds of dollars per item. The possibilities are endless. Any time and energy you can give towards making this year’s event another success is much appreciated!

A solicitation letter describing Oley and the auction is available online at www.oley.org/documents/2012_Silent_Auction.pdf, or call (800) 776-6539 for copies. If you’d like, we can send you Oley brochures as well.

You can bring items with you if you are joining us for the conference, or you can ship items directly to the Crowne Plaza. Please plan for the items to arrive by June 23 and send to:

Cathy Harrington, Guest
Hold for Arrival on 6/23/12
c/o Crowne Plaza Redondo Beach and Marina Hotel
300 North Harbor Dr.
Redondo Beach, CA 90277-2552
RE: Oley Conference 6/25/12

Thanks a million for helping with this effort!

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Center of Experience

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

British Columbia Home Parenteral and Enteral Nutrition Program
British Columbia and the Yukon, Canada

The British Columbia Home Parenteral and Enteral Nutrition (BC HPEN) programs provide support to consumers within British Columbia and the Yukon. The PN program cares for about seventy adult and a few pediatric consumers. The EN program cares for about twenty adult and one hundred pediatric consumers. Both programs provide support to consumers with intestinal failure.

The adult programs operate out of St. Paul’s Hospital, a large acute care, teaching, and research hospital in Vancouver, BC. St. Paul’s is part of the umbrella organization Providence Health Care (PHC). The pediatric programs are largely operated out of BC Children’s Hospital in Vancouver, BC, which is part of the Provincial Health Services Authority. PHC manages the financial administration of both the adult and pediatric components.

The programs’ stated mission is: “to provide outstanding, comprehensive healthcare based on current scientific principles and international standards of practice for intestinal failure patients living in BC and the Yukon; and to be a clinical and educational resource for healthcare providers.”

For more information visit www.bchenhpn.com, e-mail homePEN@vch.ca, or call (877) 806-9353 or (604) 806-9353.
The Latest Trends in Parenteral and Enteral Nutrition

Lisa Metzger

Clinical Nutrition Week is the annual conference of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). In January, over two thousand clinicians met in Orlando to attend sessions focused on the latest developments in—and some of the basics of—enteral and parenteral nutrition (EN and PN) and related topics. Oley Foundation board members, staff, and volunteers were there to learn, network, and share information—and to watch Oley past president Rick Davis receive the Lyn Howard Nutrition Support Consumer Advocacy Award.

Learning

Many of the topics covered at CNW that concern homePEN will be (or have been) covered in the Oley newsletter and at the Oley annual conference. Coping with drug shortages was a hot topic, and we learned more about A.S.P.E.N.’s patient registry, Sustain (see article on page 4). We attended classes on lipids in PN; optimizing EN formulas; drug interactions; gastroparesis, dysphagia, short bowel syndrome, and malabsorption; intestinal transplantation; and much more.

Teamwork in managing patient care was emphasized in more than one session at CNW. “Bundles,” standardization, “evidence-based practices,” hospital IV teams, checklists, and communication are all part of the discussion on improving care and outcomes. A model from the aviation industry, which includes a pilot consulting with the crew and following a checklist before taking to the air, has been proposed as a model for hospitals. In the keynote address at CNW this year, Albert Bothe, Jr., MD, FACS, pointed out that even cowboys—who’ve long symbolized independence and autonomy—no longer work alone, but instead rely upon a team to rally the herd. As they take hold, these trends will be beneficial to all patients, and especially to homePEN consumers, whose care is often managed by more than one health care provider.

The homePEN consumer’s perspective was the topic of an Oley-hosted focused learning session at CNW. The small group setting allowed clinicians to have in-depth discussions with Oley members and staff, and ask questions about topics they might not be able to discuss in a clinic or hospital setting—or topics that may not even occur to them. Many were surprised by Oley member Barb Klingler’s stories about SCUBA diving—something they may not have thought possible for someone on PN!

Networking

Between sessions, the Oley booth in the exhibit hall was a beehive of activity. Bob and Mary Smithers were among the dozen volunteers who answered questions at the booth. Bob and Mary also participated in Oley’s focused learning sessions. Please read Bob’s thoughts on CNW on page 9.

Rick Davis Recognized

One of the highlights of CNW for the Oley Foundation is watching a homePEN consumer receive the Lyn Howard Nutrition Support Consumer Advocacy Award. Developed in honor of Oley co-founder and A.S.P.E.N. member Lyn Howard, MB, FRCP, the award is given to an HPEN patient/consumer, family member, or caregiver who has performed admirable activities and heroically advocated for others. “Rick is an outstanding leader and an advocate for greater funding, education, and outreach to help others who use home parenteral and enteral nutrition,” said Debra S. BenAvram, CAE, Chief Executive Officer, A.S.P.E.N. “He is truly an inspiration to others and deserves this recognition.”

Receiving the award, Rick said, “Several years ago, there was an article about me in our local newspaper. A few months later, a stranger came up to me and said, ‘…You saved my life!’ He explained that he, also, had had a stroke and that he had felt sorry for himself until he read the article. He said it encouraged him to get up and exercise to regain his strength. As a result, his life had improved dramatically….At that moment, I decided to deliberately share my story.”

Believing that a picture is worth a thousand words, Rick held a bottle containing his EN formula over his head as he spoke. When he started EN, he explained, he tolerated the formula poorly and it had to be administered very slowly. It took about ten hours each day. But, he said, “The Oley Foundation gave me the tools for self-improvement, and a platform to reach out to other consumers….Oley members taught me how to manage my therapy around my life, rather than managing my life around my therapy.” In the two minutes Rick spoke, the bottle fully drained.

We offer our congratulations and thanks to Rick, for all he has contributed to the homePEN community. Please read more about Rick’s contributions as Oley president in the article that begins on page 1.
Behind the Booth: Oley at CNW

Bob Smithers

My feet hurt, my legs ache—and I had a blast. Mary and I just got home from Clinical Nutrition Week 2012 in Orlando, where we volunteered at the Oley Foundation booth in the exhibit hall. What a wonderful experience, being able to meet and talk with suppliers, dietitians, pharmacists, and doctors visiting the Oley booth and also being able to sit in on some conference sessions, not to mention “hanging out” with the Oley gang. It was our first time volunteering at an Oley exhibit booth, and it was well worth it.

In addition to meeting and greeting new and old friends of the Oley Foundation, we were able to talk with other exhibitors, nutritionists, physicians, and pharmacists, and pick up valuable information (and even a few “freebies”). We saw friends of ours from our local Gainesville, Florida, medical community, and met and talked with people from around the country and around the world.

We participated in the Oley Foundation’s roundtable session, and we hope we helped spread the message about Oley. According to Joan [Bishop, Oley’s Executive Director], in the “old” days she had to stand in the aisle and grab people to bring them to the Oley booth. In 2011, the fact is that a great many conference attendees stopped by the Oley booth just to say hello, as the Oley Foundation is now well known and highly regarded among Nutrition Week attendees. Unfortunately, in our experience, the same is not true for a large number of the physicians we have encountered in our local community. We are spreading the word.

Visitors to the Baxter Healthcare booth at A.S.P.E.N.’s Clinical Nutrition Week were invited to help “Make a Difference” and support a donation to the Oley Foundation by having their picture taken and posted on a large wall video screen in the booth. The video screen was a wall of faces by the end of the conference, and each participant received a postcard thanking them for helping make a difference in support of Oley.

A check in the amount of $5,000 was presented to Oley Executive Director Joan Bishop. The donation will help support Oley’s various programs.
Choosing Home Care, from pg. 2

required to obtain a license to do business in a state. While some smaller agencies may not want to spend the money to obtain multiple licenses, larger agencies often have branches in many states. This is especially important if you do a lot of traveling for long periods of time. Some home care companies simply won’t ship to other locations—license or not.

If you are going to travel, you will have to consider how you are going to replenish your nutrition-related supplies after your initial supplies are exhausted. Will your company be able to ship to you or do they have any special arrangements with other home care agencies that can supply you where you are going? If necessary, can the agency obtain premixed parenteral nutrition formulas, which have extended expiration dates? Will the agency charge extra for any of these services?

Supplies

Another important consideration is what kind of equipment and supplies the agency will provide you. Are there limitations to the number and types of pumps, catheter supplies, dressing kits, and/or enteral formulas available? Or will they provide to you, within reason, alternatives that fit your particular condition or lifestyle? How difficult is it to obtain an “off formulary” pump? (While you may be able to get one, will you have to fight to get it?) Will they provide you, at no additional charge, additional pumps if you are traveling or have other special circumstances?

Does the agency deliver your supplies? A few institutions and agencies still require that the consumer pick up the supplies. If the agency delivers, do you have to be home for the delivery? Will the agency provide a refrigerator for supplies? Is it easy to order supplies?

Additional Considerations

• Determine how important it is to have a company that will be with you from beginning to end—there with your first bag of HPN and there with your last can of formula.
• Are they concerned about your quality of life? For example, will they help you take on something new, like an exercise plan? Or help you work your infusion schedule around your job or a special event?
• Do they have resources to help improve your quality of life?
• Do you both have the same goals for your outcome?
• How does the company handle obtaining orders from your physician?
• Will the agency notify you of drug or product shortages, and keep you updated on how they are handling shortages?
• Will the agency notify you of any product recalls?
• Will the agency advocate for you as an HPEN consumer?
• Does the agency treat you well?

Conclusion

There are many questions you should ask yourself and others when evaluating the quality of a home care agency. You must determine what qualities are most important to you, and whether you are satisfied with your current agency. Even if your agency doesn’t provide all of the benefits you would like, you may feel a sense of loyalty to them because they have served you well for a long time. Don’t be shy about asking them if they can provide additional services or supplies that can benefit you. The worst they can say is no. ¶
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 2012 in the Jan/Feb 2013 issue. Between January 19, and March 23, 2012, gifts were received:

In Memory of
Jacques Alexander, Angelo DiMonte, Carol A. Ehlers, Franky Friedman, Nader El Samaloty, Flute Snyder, and Roger Stroud

In Honor of
Iris Chappieear; Diana Kerrigan; and Ann and Tim Weaver, for their continued support of pharmacy education at MWU

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

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.

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

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

BRONZE STAR PARTNERS
($20,000–$29,999)
Baxter Healthcare

BENEFACCTOR LEVEL PARTNERS
($10,000–$19,999)
Abbott Nutrition
Emmaus Medical, Inc.
InfuScience, Inc.
Kimberly-Clark

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

CONTRIBUTORS
($1,000–$2,499)
B. Braun Medical

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. To learn how you can make a difference at (800) 776-OLEY.

Felice Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Cottet
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Tom Diamantidis, PharmD
Selma Ehrenpreis
Herb & Joy Enich
Jerry Fickle
Don Freeman
Linda Gold
Linda Grovenstein
Deborah Groeber
The Groeber Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelder
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Maranen, PhD, RD, CNSD
Kathleen McInnes
Michael Medwar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh, & Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
Clements Pitzauer
Beverly Promisel
Abraham Rich
Gail Egan Sansivier, MS, ANP
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnol
Doug Seidner, MD, FACC, CNSP
Judi Smith
Steve Svensen
Cheryl Thompson, PhD, RD, CNSD,
& Gregory A. Thompson, MD, MSc
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Roseline Ann & William Wu
two three-year terms. We’d like to thank Rick and Dr. Balint, and introduce you to Mary Patnode, MS Ed, the new Oley president, along with new trustees Terry Edwards, Darlene Kelly, MD, PhD, and Ann Michalek, MD.

In the five years he served as president, Rick raised the foundation’s profile and the public’s understanding of nutrition support, particularly tube feeding. In fact, Rick, who has been on enteral nutrition (EN) since a stroke left him unable to swallow, received the Lyn Howard Consumer Advocacy Award from A.S.P.E.N. in January (see page 8), as well as Oley’s Celebration of Life and Lenore Heaphey awards (in 2005 and 2006, respectively). Rick was an Oley Regional Coordinator (RC) before he became president. He is always willing to talk to other consumers and caregivers; has presented the patient perspective before clinicians; and shared coping techniques at conferences. Rick has been featured in articles in local and national media, raising awareness that you can be active while on tube feeding. In 2009 he hiked the Grand Canyon rim to rim—raising awareness and funds for Oley. As president, Rick will also be remembered for the professional skills he shared, which helped sharpen Oley’s image and operations.

Dr. Balint, a gastroenterologist at Nationwide Children’s Hospital, Columbus, Ohio, frequently serves Oley as a resource on pediatric issues. She has a long history with Oley; her father, John Balint, MD, was a founding board member. Dedicated to serving homePEN consumers, Dr. Balint received Oley’s Nan Couts Award in 2005. We are grateful for her many contributions.

Mary Patnode, the new Oley Foundation president, has been on parenteral nutrition (PN) since 1980 due to Crohn’s disease. A retired school psychologist, Mary has been on the board since 2009 and has been an Oley RC since 1987. She is familiar with the issues that matter to Oley members, and brings a thoughtful, balanced view to the position. We look forward to working more closely with her.

Terry Edwards has been on EN since 2005, after having a tumor removed from the base of his brain. He has attended several Oley conferences and represented the consumer voice at professional meetings. Terry lives in Vancouver, Canada, and travels frequently in the United States and internationally.

Dr. Kelly chairs the Oley Research Committee and has served on the board in the past. After a three-year hiatus, she has agreed to join the Oley board again. Dr. Kelly is a frequent contributor at Oley conferences and to the newsletter, and often helps answer members’ questions. She has been the Medical Director of the Home Parenteral Nutrition Program at the Mayo Clinic, Rochester, Minnesota, since 1991.

Dr. Michalek specializes in Clinical Nutrition at Albany Medical Center, Albany, New York. She completed her fellowship with Oley’s co-founder, Lyn Howard, MD, and assumed responsibility for many of Dr. Howard’s patients when Dr. Howard retired in 2007.