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Oley is a national, non-profit organization that provides information and support for consumers of homePEN, their caregivers and clinicians.

All Oley services and educational materials are FREE for consumers and their caregivers.

Oley programs:

- **LifelineLetter**: a bi-monthly newsletter with articles about medical advances and personal experiences,
- **Regional Coordinator Network**: a national grassroots network of 70 volunteers — all homePEN consumers or caregivers — who provide outreach and education at the local level
- **National and Regional Conferences**: opportunities for homePEN consumers, clinicians, providers and industry representatives to share support and information
- **Information Clearinghouse**: a resource designed to answer questions about homePEN through a toll-free hotline, world wide web page and video tape library
- **Toll-Free Consumer Network**: a networking tool that provides free access to different experienced homePEN consumers around the country, each month
- **HomePEN Family Network**: a support network for children on either therapy and their families

LifelineLetter

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

Home Parenteral Nutrition: The Consumer's Perspective

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Adjustments in relation to their body, environment, family and friends are just a few of the many challenges facing consumers of home parenteral nutrition (HPN). By isolating and understanding some of the more common situations, one can better appreciate many of the psycho-social issues associated with HPN. A consumer's ability to recognize and manage these issues would seem critical to ensuring compliance and maximizing rehabilitation. The following article is meant to open the dialogue between consumers, their families, and clinicians. It is based on a focus group of several seasoned HPN consumers organized by the Oley Foundation in November of 1998.

The HPN Consumer

The majority of long-term HPN users fall into two broad categories: consumers who were previously well and then experienced a catastrophic event that significantly affects their body's ability to absorb nutrients (e.g. mesenteric thrombosis, or midgut volvulus); and consumers with chronic gastrointestinal medical conditions (e.g. Crohn's disease, intestinal pseudo-obstruction) who, because they have not adequately responded to less invasive therapies, are put on HPN as a "last-resort" life-saving treatment. The differences between these two groups contributes majorly towards a consumer's initial acceptance of HPN; but in the long run, acceptance and compliance are unique, not to the underlying disease or condition, but to the individual.

Acceptance/Compliance

Many consumers find it difficult to accept their dependence on HPN and all of the restrictions that go along with it. This includes everything from scheduling work and activities around infusion time, to the extra planning and precautions the consumer needs to take before they can enjoy such activities as swimming and traveling. As one consumer describes it, "I find it difficult just to accept that something is wrong with me let alone that I have to deal with the consequences of my illness....Maintaining my compliance is a daily battle. I infuse every day, but I'm very aware that I have to be compliant to do this."



Don Young, HPN consumer, hooking up at home.

Viewed in this manner, acceptance is often an issue of control that needs to be addressed for the consumer to successfully adjust to the long term use of HPN. This issue is compounded by the level of uncertainty most HPN consumers face because of their medical condition; consumers can't predict exacerbations of their disease, complications from the therapy, hospitalizations, absences from school or work, etc. While the consumer can't "control" these events, they can control certain factors influencing them to minimize their occurrence and unpleasantness. It is not surprising then, that compliance becomes less of an issue for consumers if they are encouraged to exercise what control they realistically can have over their therapy. To do this, they need to become partners in the decision making. For example, whenever possible, consumers should be given a choice of catheter device and infusion time. For this to work, the consumer needs to educate themselves about HPN and to develop a good working relationship with their physician. Having another HPN consumer to empathize and share experiences with, can also make compliance easier.

Sleeping Issues

One of the more difficult physical adjustments for HPN consumers is how to regulate their sleep/wake cycle. Sleep deprivation, primarily from frequent

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nighttime bathroom visits, is an all too real occurrence that often exhausts not only the consumer, but also family members and caregivers. Some consumers attempt to limit the disruption from frequent bathroom visits by keeping a portable commode next to the bed for easier night voiding. Sleep can also be affected by the infusion process and equipment; some consumers have trouble finding a comfortable sleeping position that minimizes the likelihood of tubing leaks and disconnections, or line occlusions and pump alarms. Although most of the newer, user-friendly infusion devices are relatively quiet,

some noise is inevitable. Additional sleep-related issues include morning fluid retention and nausea, particularly following nighttime lipid infusions.

A few consumers have coped with sleep-related disturbances by infusing some or all of their HPN during the day. One HPN consumer who, until recently, infused only during the night, describes her experience with daytime infusions: "The difference in how I feel is tremendous. I now sleep through the night, getting up only once or twice...I have more energy and I no longer have those dark circles under my eyes." Besides being better rested, consumers who infuse during the day feel they have more energy because the TPN calories are immediately available to meet their energy requirements. They are also less likely to suffer from daytime dehydration and muscle cramps related to electrolyte shifts.

Infusing during the day is a personal, quality of life choice. Portable HPN pumps are readily available, yet many consumers fail to realize that such an option exists. Barring any medical contraindications to daytime infusions, offering the consumer the option of infusing at night or during the day has the additional benefit of permitting the consumer to exercise some control over their condition.

Body Image

The central line catheter itself can be an issue for HPN consumers, as it can be perceived as one more insult to their body image. This is especially true if the line was unexpected. The type and location of catheter can make a difference in how the consumer accepts the catheter. An external catheter is a constant visual reminder of the consumer's dependence on HPN and underlying medical condition. It may restrict a consumer's choice of clothing and complicate certain activities, such as showering, swimming and participating in sports. An implanted port, on the other hand, is placed under the skin and is generally much less restrictive. [Editor's Note: An implanted port is only safer for showering and swimming when the needle is out. A needle in the port causes the same risk of contamination as an externalized catheter.] With proper support, most consumers' level of comfort with their body prior to TPN can carry forward to the post TPN period.

Oral Nutrition Issues

Although a small percentage of HPN consumers are unable to consume food orally, most HPN consumers can; and this is strongly encouraged by most physicians, even when some dietary restrictions are necessary. Since our culture focuses many of its social gatherings around food, meals can be of great concern to consumers who cannot eat, or whose intake is limited; not surprisingly, they find it difficult (at least initially) to enjoy a meal or social occasion. Despite these barriers, many long-term consumers find it is important for them and their families to maintain their participation in the "normal" family eating routine. For example many consumers have a place set for themselves at the table, and join the rest of the family for the social, if not nutritional, aspects of the meal. The consumer's personal level of comfort with his modified eating will often help those around him feel more comfortable about his altered eating habits.

Parents and caregivers of children on HPN routinely express concern about their child not wanting to eat. This stems from the early period of a poorly working gastrointestinal tract, which frequently leads to vomiting. Several parents who have successfully cleared this hurdle preach patience, patience, and more patience. One intuitive parent states, "Training a child to eat falls under the category of art, not science. Some creativity must be in order to help the child to progress." Professional help is often needed for children who lack eating skills.

Employment

While some HPN consumers can and do work, many others cannot. Paradoxically HPN therapy often restores a consumer's health to a level where they are physically able to work, at least part-time, but they can't return to work because they need "disability" insurance coverage to afford their HPN. Part-time work seldom offers insurance benefits. Additionally, the need for a generous insurance package to cover HPN, may prohibit a consumer from taking a full-time job or from being hired.

For some consumers, volunteer work is acceptable. For many, however, the question "What do you do?" is unsettling. Regardless of one's education, income and social status, work itself has an intrinsic value that is

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difficult to relinquish. In the words of one consumer, “I know I’m still the same professional, that volunteer work challenges my brain; yet there is still a part of me that feels inadequate in that I could not continue to work on my terms. The innocent ‘What do you do?’ makes me teary-eyed.” On a more positive note, several recent regulatory initiatives — such as the Health Insurance Portability and Accountability Act and the broader interpretations of COBRA rights — are making health insurance more accessible, and thus, paid work a more viable option for HPN consumers.

Friends & Family — When to Tell

Consumers may find it difficult to discuss their condition with others because HPN is a relatively uncommon therapy, and because it includes bodily functions that most people consider private. For the single adult consumer, discussing HPN may be particularly difficult with someone they may wish to date. While it primarily depends on the consumer’s personality as to how much they want to explain and when they feel comfortable discussing such matters, it also depends on the other person’s curiosity and willingness to know. A common approach used by many consumers is to give some form of a vague explanation, such as “my stomach cannot digest food” or “my intestines don’t work.” Such statements will often spark the other person’s curiosity, prompting questions, which then permit the consumer to respond in a manner appropriate to the situation at hand. Some consumers use this opportunity, through humor or otherwise, to teach others about their unique way of eating. As one consumer likes to joke, “How many people do you know who can eat and have a root canal at the same time?”

Sexual Relations

HPN therapy should not preclude a medically-stable consumer from having sexual relations, but it can be inhibiting both physically and psychologically. Because of the serious medical issues that are being addressed, this important topic is often innocently overlooked by the treating physician or it is left for discussion at another time. Consumers may be concerned about dislodging the catheter, conceiving while dependent on HPN, or en-

gaging in intimate activities while they are “hooked-up.” Additionally, they may be uncomfortable with their body image or with discussing sexual issues with their partners.

Support from a physician, or other health care professional (nurse, psychologist, counselor, etc.) can help consumers become more comfortable with these issues. Since sexual relations can be a significant issue for the partner as well, couples should be encouraged to come together to an appointment to discuss their concerns.



HPN has been a double-edged sword. On the one hand, it has been nothing short of miraculous; I went from practically living in the hospital to really living. On the other hand, I can’t help but worry about what will happen if I run out of access sites, if my liver malfunctions, or if my insurance runs out.

Dependence on HPN

HPN is not a disease; it is an “enabling” therapy that is the lasting result of a traumatic accident or a symptom of chronic illness. For those consumers who will never be able to sustain themselves without HPN, there are a multitude of never-ending stressful issues related to their dependency: from securing adequate insurance coverage for the therapy, to retaining access sites, to avoiding long-term complications such as bone and liver disease. As one consumer vividly describes, “HPN has been a double-edged sword. On the one hand, it has been nothing short of miraculous; I went from practically living in the hospital to really living. On the other hand, I can’t help but worry about what will happen if I run out of access sites, or if my liver malfunctions, or if my insurance runs out.” The fear of stopping HPN, whether it be out of necessity or by choice, is very real.

Consumers whose dependence on TPN is more borderline, often have the same worries and additionally may need to overcome a “psychological addiction” to HPN. Typically a consumer with such an addiction has experienced a significant improvement in their

quality of life since beginning HPN, and perceives that without HPN their underlying condition will worsen and they will again become malnourished. Obviously, each case is unique, and getting over this addiction depends not only on the consumer’s past and present state of health, but also on the quality of the doctor/patient relationship. Several consumers also stress the importance of timing, stating that physicians often suggest stopping HPN when consumers feel they need it most. For example, when they’ve been in hospital for treatment of sepsis.

Finding Help

While HPN consumers who have chronic medical conditions are apt to adjust to life with HPN easier than those who were previously well and experience a catastrophic event, most people on HPN experience what one consumer describes as “an emotional roller coaster.” For many, the “ups” and “downs” are most pronounced following hospitalization. In the words of one consumer, “Each time I return home from the hospital, no matter how happy and relieved I am to be free again, to be declared well, I re-experience my great vulnerability and I become depressed. I then get angry at myself for being depressed. While I understand my feelings, I can’t escape them.”

Anger, fear, depression and the whole gamut of emotions are common, but they need not be overwhelming. To deal with these emotions, and the host of psycho-social issues causing them, many HPN consumers seek professional help or reach out to others on HPN. Dealing with these issues and finding workable strategies, not only improves consumers’ quality of life, but it can also improve their health by ensuring better compliance with the therapy. Physicians managing TPN should be able to recommend counseling resources to consumers in their community. In addition, the Oley Foundation for home parenteral and enteral nutrition can provide information and psycho-social support for HPN consumers through a host of networking and information services. For more information contact the Foundation at 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208; (800) 776-OLEY/(518) 262-5079; E-mail BishopJ@mail.amc.edu; <http://www.oley.org>. ©