

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)

Living with Enteral Feeds: An Exploration of the Physical and Psycho-Social Issues

Coping with body changes, cumbersome tubing and new family dynamics are just a few of the many challenges facing consumers who begin home enteral nutrition (HEN) feedings. The following article will review some of the major concerns of HEN consumers and is meant to open the dialogue between consumers, their families, and clinicians. It is based on a focus group study of several HEN consumers which took place in September of 1997. Many thanks to the participants who spoke openly and candidly about their concerns.

Physical Adjustments

Once HEN consumers begin using their nasogastric (NG), gastrostomy (G) or jejunostomy (J) tube, they undergo many physical adjustments. Those who use NG-tubes, for example, may have trouble inserting the tube and may experience painful irritation in their nose and throat. On the other hand, gastrostomy- and jejunostomy-tube users have to cope with skin care and irritation at the insertion site, leaky tubes and bulky tubing that is often visible through their clothing. Bulky tubing and/or the position of the insertion site can make dressing difficult as well, since both may end up at the waist line.

HEN consumers also face the challenges of learning how to sleep, use the lavatory or have sex while they are hooked up. Other common physical adjustments include learning how to manage a pump and how to deal with a clogged tube.

Simply leaving home can be a physical challenge to consumers on HEN. For some, diarrhea and cramping are a way of life, and if you have no ostomy, there is a potential for bowel accidents. Fortunately there are measures that can help control the diarrhea, for example switching formulas, taking medication and adjusting feeding rates. As the bowel adapts, the diarrhea and/or accidents may diminish as well.

In terms of making other physical adjustments to HEN easier, almost all consumers agree that there should be more instruction offered at the hospital. Simple steps like learning how to properly secure the tube externally can help avoid problems with leaking, skin irritation and dressing. Likewise, having a portable (vs. pole-mounted) pump and more in-



HPEN consumers, Malisa Matheny and Colyn Woods compare tubes.

struction on using it, can go a long way towards making a consumer more comfortable and accepting of their new situation.

Another important part of making the physical adjustment to HEN easier, is open communication between the physician and the consumer. "The consumer needs to hear from the physician managing their nutrition that 'You will be uncomfortable. There will be pain and leaking, but, enteral is much better for you physically,'" explained one consumer. Simply knowing what to expect ahead of time can help considerably. It takes away the fear of the unknown, and allows the consumer to prepare themselves physically and mentally for the change. Should the physician be less communicative, it is up to the consumer to ask about these important issues and potential solutions or resources the physician can offer.

Psycho-Social Adjustments

Body Image

Beyond the physical adjustments to HEN, there are a host of psycho-social issues that make adjusting to HEN challenging and can lead to many emotional ups and downs. First there is the issue of the consumer coping with his or her new body image. Whether it's the tubing, the insertion site or the equipment, there are adverse physical changes in the

HEN, from pg. 1

consumer's body that can dramatically degrade their self image. "You get very mad at your body," describes one consumer, "and there is often some depression with it. You have to be very disciplined with yourself or you can just slide into these funks." How the consumer felt about their body before

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The Oley Foundation
For Home Parenteral and Enteral Nutrition
214 Hun Memorial, A-28
Albany Medical Center
Albany, NY 12208
1-800-776-OLEY, or (518) 262-5079
Fax: (518) 262-5528
E-mail: BishopJ@mail.amc.edu
DahlR@mail.amc.edu
WilsonE@mail.amc.edu
HarrinC@mail.amc.edu
Web page: www.oley.org

Executive Director:

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the tube was inserted and their medical history can affect their adjustment to their new body image as well.

Next there is the issue of dealing socially with the physical changes that accompany HEN. Since the general public is usually unaware of HEN, consumers may be stared at, questioned about their equipment or become the victim of mistaken presumptions. NG-tubes in particular are clearly visible and draw attention. Even consumers who have a "button" closure to their gastrostomy, the least visible HEN appliance, experience comments and stares from time to time. As one HEN consumer describes his vacation at the beach, "At first I was self-conscious about revealing my button. Later I thought 'Why am I wearing this t-shirt?' and took it off, but everyone would stare at me. Now I put a Band-Aid® over the button, which helps."

Sexual Activity

Sexual activity is another important issue. Single consumers find that HEN can complicate their dating efforts, and other consumers find their spouse or partner is no longer interested in intimate or sexual activity. Whether it is the disease, the feedings or the equipment that puts the sexual partner off, a decline in intimacy can be a very painful and difficult issue. For most consumers it takes a lot of work to keep their sexuality alive: often it's a matter of frank discussions about sexual issues with their partner, and planning how it can physically work. For example, consumers might schedule intimate times for when they are not hooked up, and need to make sure the tubes and/or ostomy appliance are not in the way. Some consumers may also need professional help regulating their hormone levels to boost their libido, or working out a problem with impotence. Consumers agreed that physicians are often unlikely to bring up sexual issues, but that physician support can make a huge difference in helping consumers know what to expect and how to move on safely, and more assuredly, to an active sex life. Thus it is important for the consumer to raise this issue if their physician hasn't addressed it yet.

Acceptance/Compliance

Just as consumers can find it difficult to adjust to their new body image and sex life,

many consumers also find it difficult to accept their dependence upon nutritional therapy and all of the trappings and restrictions that go along with it. As one consumer describes, "I find it difficult just to accept that something is wrong with meMaintaining my compliance is a daily battle. I do it every day, but I'm very aware that I have to be compliant in order to do this." Although this issue is often overlooked, being on HEN requires a commitment from the consumer that can be more difficult than complying with a rigid diet. And for consumers who were fiercely independent prior to HEN, accepting the therapy is no small hurdle. Rest assured, however, that compliance is something that can be successfully addressed when the consumer is willing and has the proper support behind them.

Scheduling Around Infusions

Another challenge for HEN consumers is adjusting their daily life to fit with their infusion schedule. For consumers who don't have a portable pump, or if for another reason it's impractical to infuse publicly, the need to be at home and hooked up for several hours during the day or evening can put a real cramp in their social and business life. On the other hand, consumers who travel a lot for work or are on around-the-clock feedings are forced to infuse in front of strangers, clients, co-workers, fellow students, and so on. This naturally leads to some anxiety about being accepted by their peers and how their perceived "disability" will affect their interactions. Taking HEN out of the home also necessitates extra planning and baggage whether you are traveling around town or around the world.

Not Eating

HEN consumers also find it challenging to not eat when the rest of their family, friends or co-workers are. It's a real adjustment learning how to gracefully enjoy a meal or social occasion without eating — especially when being pressured to eat by restaurant staff or group members unfamiliar with HEN. One consumer says she and her husband developed a whole new language to explain quickly and easily why she wasn't eating to his clients that they entertain. In addition to making others around them understand the issue, it's difficult for

consumers themselves to face the fact that they cannot eat. Many consumers miss the oral pleasures of taste and texture as well as the social interaction of eating out. To compound the problem, most social gatherings center around food. As one consumer explains, "Going out to dinner and not eating is very difficult for me. So is cooking for my family and shopping for food. In our culture we seem to eat a lot. Our family will get together for something, Sunday dinners, whatever, and everybody is always eating."

In dealing with many of these social issues, most consumers find if they can show their family, friends and peers that they are comfortable with the situation, then the other parties accept them and the HEN. Depending on the comfort level of the group they are with, consumers can also find creative ways to overcome therapy-imposed barriers. For example some consumers will hook up in front of others in order to not miss out on a special event such as a slumber party. HEN consumers have also discreetly "chewed and spit-out" meals in order to taste and enjoy a special feast.

Finding Help

Generally speaking, having a supportive family and/or group of friends is an important factor in helping an HEN consumer successfully adjust to their new life. With support, consumers are better able to regain

their independence and self confidence. Consumers seem happiest in relationships where family members and friends are able to provide acute physical or psycho-social support when needed, but are also able to back off and encourage independence when the consumer is well again. "My husband

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expects me to continue on with my life, in as much as possible a normal way. He is very supportive. And once in awhile if I get into one of these undisciplined funks, he helps me get back on track," explains one consumer. Many HEN consumers find that in overcoming the challenges of HEN and their underlying diagnosis, they have built stronger interpersonal relationships with their families and friends.

Another suggestion for dealing with the physical and psycho-social needs of HEN patients is to consult with a specialist. Depending on the consumer's needs this can mean a psychologist who can help work out problems with body image, compliance and

the like; an enterostomal therapy nurse who can help with skin care at the insertion site; a dietitian with training in nutrition support who can help consumers maximize their oral intake; or a consumer advocate who can help resolve reimbursement issues such as acquiring a portable pump.

Other resources that can help make the physical and psycho-social adjustment easier for consumers are available through the Oley Foundation's information clearinghouse and regional coordinator network. This includes videotapes and articles which overview skin care, tube care, personal experiences and other pertinent topics, as well as the ability to network HEN consumers and family members with other experienced consumers.

Moving forward, many consumers find fulfillment and empowerment by learning as much as they can about their particular diagnosis/condition and therapy, and then participating as fully as possible as a part of their health care team. Although self advocacy is not welcomed by all clinicians, building a better relationship with your health care team can significantly improve your care and is definitely worth the effort.

Comments on this article are welcome and can be mailed to: LifelineLetter Editor, c/o The Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208; faxed to: (518) 262-5528; or e-mailed to: DahlR@mail.amc.edu. ©