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# LifelineLetter

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

## Down Home with Nancy Harvey

Bright and principled, 49 year old Nancy Harvey has a well-balanced, practical and spiritual approach to life and its many challenges. Nancy has had Crohn's disease since she was in her early twenties. Her Crohn's was exceptionally severe, with no remissions, and as she recalls, "there were few treatment options back then." In 1980, following a major bowel resection, she ended up on TPN. Luckily, she is able to eat what she wants, although with her short bowel, she watches her intake before going out.

The bulk of her nutrition is taken at night. Nancy infuses a 3-liter bag of TPN over 12 hours. Her husband, Jim, plays a big role in her care. "Jim grew up helping out at home, so helping out around our house and with the TPN is no big deal to him," says Nancy. He and Nancy enjoy the time they spend together hooking up each night. As she explains "It's always been a good time for us to chat." Although she admits that, "Sometimes, if we're not careful, we start talking and forget where

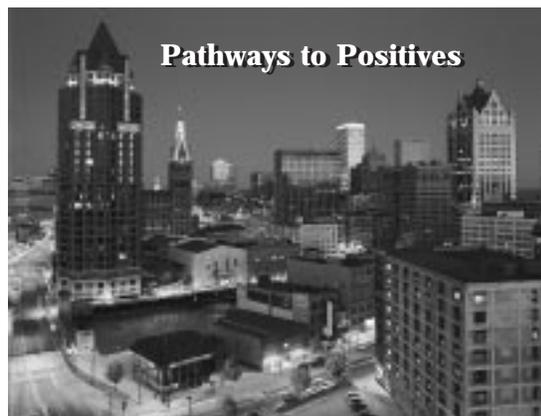


Three of Nancy's feathered companions: Snowflake (left), Samantha and Josephine.

we are in the process — which can be a problem."

Nancy and Jim live on two acres outside Jefferson City, Missouri, with their many animals: geese, ducks, four dogs and two cats. She jokes that with her short

Nancy cont., pg. 2



## Help Plan the 2001 Oley Conference

Plans are underway for the 16th Annual Oley Consumer/Clinician Conference, and the Oley Foundation needs your ideas. Specifically we're wondering what topics you'd like to see covered during the plenary and breakout sessions. Consumer and clinician input is welcome!

The conference will be held at the Hilton Milwaukee City Center, June 21 to 23, 2001, in Milwaukee, WI. Call, write or e-mail your ideas to Joan Bishop at the Oley Foundation (contact information is on page 2).

## Alteplase Safely Clears Catheter Occlusions

Most homePN consumers and caregivers have dealt with the frustration of an occluded catheter. Restoring the catheter's function (and thus the consumer's ability to infuse HPN, hydration, antibiotics, etc.) is not only critical to the consumer's well being, but also to their ability to retain lifelong access. Catheters may be occluded by a thrombotic, mechanical or other obstructions. Studies show that more than half (58 percent) of catheter-related occlusions are thrombotic, resulting from the formation of thrombus within, surrounding or directly outside of the catheter. Until two years ago, these catheters were treated with urokinase.

In 1999, the Food and Drug Administration (FDA) severely limited the availability of urokinase, and since then, clinicians (and consumers) have been urgently seeking information regarding appropriate ways to use other agents to treat thrombosis-related catheter occlusion. Lifeline readers will recall Barbara McKinnon's article in the March/April 2000 *LifelineLetter* which reviewed three alternative 'clot busters': streptokinase, alteplase and reteplase

Alteplase cont., pg. 4

### Nancy, from pg. 1

bowel syndrome, she relates well to the geese's quick digestive system. Her main companions, though are the dogs — most of them mutts she found abandoned. They're all different sizes, and all react differently to the TPN. "One of the dogs is afraid to be near me when I'm infusing," she explains, "and another is very protective." A third dog even sleeps with Nancy when she's hooked up!

According to Nancy, pets provide good companionship and shouldn't be too much of a safety concern for consumers to keep in their home. She stays away from the cats when she is infusing, and is careful when she pets them

(to avoid a scratch which could get infected), but so far she's had no problems. Well, almost no problems. Once, many years ago, she was sleeping when a thunderstorm woke up her German Shepherd. He was scared, and as he jumped up, he got tangled in the lines. He ended up pulling the spike from the bag. "It was a big mess, but it sure was funny," she recalls. "It was back in the days when I used to mix my own bags. So while Jim mopped the floor, I just mixed another bag and hooked up again."

#### Be Happy: Stay Active

Nancy has taught French for most of her adult life. She stopped working two years ago because of a complication from breaking her leg. At the time, her catheter was in the leg that was broken. She had trouble healing from the pin they inserted and eventually her line became infected, leaving her with one good vein for TPN.

Even though she's retired, Nancy stays busy. She and Jim moved to a new home, where she volunteers at the school up the road. She shops; she enjoys cooking for family and friends; and has even taken to writing. She's had three articles published, two on euthanasia (accessible on the internet at [www.FirstThings.com](http://www.FirstThings.com), search by author "Nancy"). Her interest in the topic stems from her experience with her own health problems. She feels consumers are at risk.

"TPN afford us a good quality of life, but it's terribly expensive. Some people don't understand, and may feel it's not worth paying for," she explains.

Her advice to other consumers who aren't working, is to get out and volunteer. "It'll raise your spirits," says Nancy. She suggests working with kids. "They're just thrilled to have some attention, and it's as easy as reading a story for an after-school program." She continues, "All schools are eager to have volunteers. You can help as much or as little as you like." Nancy uses a cane and says the kids clamber to help her. She thinks it's great for them to be exposed to people who are different or disabled. "It helps them realize that if challenges come their way, they can still move forward with their life," she adds.

Nancy is grateful for her strong support network and her faith. Her husband, parents and friends are all behind her when she needs them. "I was lucky. When the disease hit, I wasn't devastated because I knew what's important in life." Twenty-some years later, her disease and therapy are still just one part of her normal, full life. Her secret: "You need to reach out and enjoy life — care for the people around you. No matter how sick you are, you can still show love, and people today are starved for affection and concern." ☺



*Nancy with Mokie Beastie, a protective friend who took care to stay clear of her infusion tubing.*

### LifelineLetter

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The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Director of Publications & Information at the address above.

## Scholarships Offered



Nutrishare is offering two \$500 scholarships for TPN consumers: one towards the Spring 2001 semester and one for the Fall 2001 semester. Interested TPN consumers should write a letter describing their studies and what they plan to use their education for. (A few paragraphs is fine.) A committee set up by Oley will review the applications and choose the winners based on potential and need. The scholarship money will be distributed at the end of the semester when the

winner submits a copy of his/her grades to the Oley Foundation. Applications should be typed or word processed, and postmarked by May 1, 2001 for the Spring scholarship, and October 30, 2001 for the Fall scholarship. Applications should include the candidate's name, photo, number of years on TPN, address and daytime phone number. Send applications to the Oley Foundation (address in box on page 2). Former applicants are welcome to reapply.

## Tube Talk

Thanks to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208; or E-mail DahlR@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.

### Minimize the Pain of Silver Nitrate

If you're like me, using silver nitrate to reduce tissue buildup around your stoma site can be very painful. One suggestion is to ask your physician about numbing the area first with a drop or two of 2% Lidocaine. It should be left on the tissue area for a couple of minutes, then dabbed off, before the silver nitrate is applied. I find it much less traumatizing and more comfortable to deal with. The 2% Lidocaine may be prescription only, but a little goes a long way and certainly cuts down on the pain. (Note: because you use so little each time, it is wise to store the Lidocaine in a dark area at room temperature.)

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### Makeshift G-tube Holder

Our son Steven is a very active sleeper and we worried about him pulling on his G-tube. To hold the tube in place, we use a nametag clip. First we make a loop out of his tube, then we wrap the plastic loop from the name tag around his tube and snap it shut. The clip part we attach to his diaper. This makeshift holder gives Steven room to move around without the tube pulling on his stomach. When he had a G-J tube, we did the same thing so the tube did not dangle. (Editor's note: this tip was first published in *MUMs National Parent-to-Parent Network Newsletter*.)

— Charlene Jurysta  
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### Additional Tube-Holder Suggestions

Additional suggestions for securing a tube or catheter are available from the Oley Foundation office. Interested persons should send a self-addressed, stamped envelope to: G-Tube/Catheter Holders, c/o The Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208.

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**Alteplase**, from pg. 2

(article available at [www.wizvax.net/oleyfdn/lifeline/99-019.html](http://www.wizvax.net/oleyfdn/lifeline/99-019.html)).

After hosting a conference to study the issue, the National Association of Vascular Access Networks (NAVAN), in cooperation with several other organizations (including the American Society for Parenteral and Enteral Nutrition), has come to the consensus that Alteplase (Genentech, Inc.) is a safe and effective treatment for thrombotic catheter occlusions. Following is some information extracted from their recently published guidelines "The Use of Alteplase (t-PA) for the Management of Thrombotic Catheter Dysfunction," edited by William Haire, MD and Suzanne Herbst, RN, MA, published in the September 2000 *Clinician*. (For a complete copy of the guidelines E-mail [jpiperata@synermed.com](mailto:jpiperata@synermed.com). Please indicate the number of copies requested and include a complete mailing address.)

**Alteplase vs. Urokinase**

Urokinase has been studied extensively for the treatment of occluded catheters. While early studies reported patency rates of nearly 100 percent, members of the NAVAN consensus feel the investigators did not use objective criteria or precise definitions for catheter obstruction

and catheter clearance. Two more recent studies by Monturo et. al.<sup>1</sup> and Haire et. al.<sup>2</sup> showed that urokinase returned function to 59 percent of thrombosed catheters and removed the total clot in just 32 percent of thrombosed catheters. These studies required radiographic confirmation of the presence of a thrombus and its resolution.

Clinical trials have demonstrated that t-PA restores function in about 60 to 80 percent of treated thrombosed catheters [see Table 1]. When compared with urokinase in a study by Haire, et. al.<sup>1</sup>, t-PA restored function to more catheters than did urokinase [see Table 2]. Radiographic studies confirmed the complete resolution

Clinical trials have demonstrated that t-PA restores function in about 60 to 80 percent of treated thrombosed catheters.

**Table 1. Patency Rates Attributed to t-PA**

Source	t-PA Dose	Patency Rate
Atkinson et. al.	2 mg in 2 mL	83.0%
Haire et. al.	2 mg in 2 mL	60.7%
Maloney et. al.	0.25 mg in 1 mL or 0.5 mg in 2 mL	88.7%
Choi et. al.	0.5 to 2 mg	82.3%

of the occlusion in almost twice as many t-PA-treated catheters as urokinase-treated catheters. In addition, significantly fewer of the t-PA treated catheters required a second dose of drug compared with the urokinase-treated catheters.

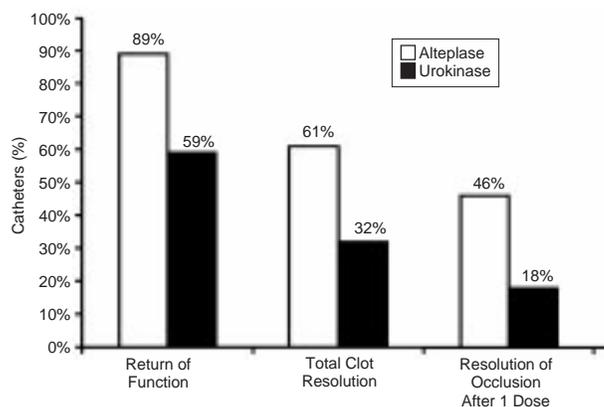
Although clinical experience with t-PA in pediatric patients with occluded catheters is limited, preliminary data are available from two clinical trials by Maloney et. al.<sup>3</sup> and Choi et. al.<sup>4</sup> which reported rates of 88.7% and 82.3% respectively for reestablishing patency.

**Dosage and Administration**

Suggested procedures for treating a partial or complete thrombotic catheter occlusion are shown in Table 3. The standard t-PA concentration is 1 mg/mL. An adequate volume of the t-PA solution (usually 1-2 mL) is used to fill the catheter, and then allowed to dwell in the catheter 30 to 120 minutes. The t-PA dose can be repeated if the first try isn't successful. If the catheter does not respond to two t-PA instillations, or if dysfunction recurs, the clinician will need to further

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**Table 2. Treatment of Thrombosed Catheters**



\*Clot resolution confirmed after one or two doses using radiographic contrast injection.

Adapted with permission from *Clinician* and Haire, WD, et al.

evaluate the nature of the occlusion.

One of the drawbacks to t-PA is that it is not convenient to use. It requires refrigerated storage and must be reconstituted prior to use. Additionally, it is distributed in 50 mg doses, when only 2 mg are typically needed for catheter clearance. Once reconstituted, t-PA can be frozen for future use in individual doses and stored for up to one month [see Table 4].

The larger distribution size means cost can also be an issue. When t-PA is repackaged in 2 mg doses its cost is comparable to urokinase, but smaller institutions may not use all 25 doses before their limited shelf life expires.

The manufacturer of t-PA (Activase®, Genentech, Inc.) is seeking FDA approval for using t-PA for catheter clearance, and hopes to have it by late summer 2001. If the drug is approved, the company will be looking into distributing the drug in a more convenient 2mg vial.

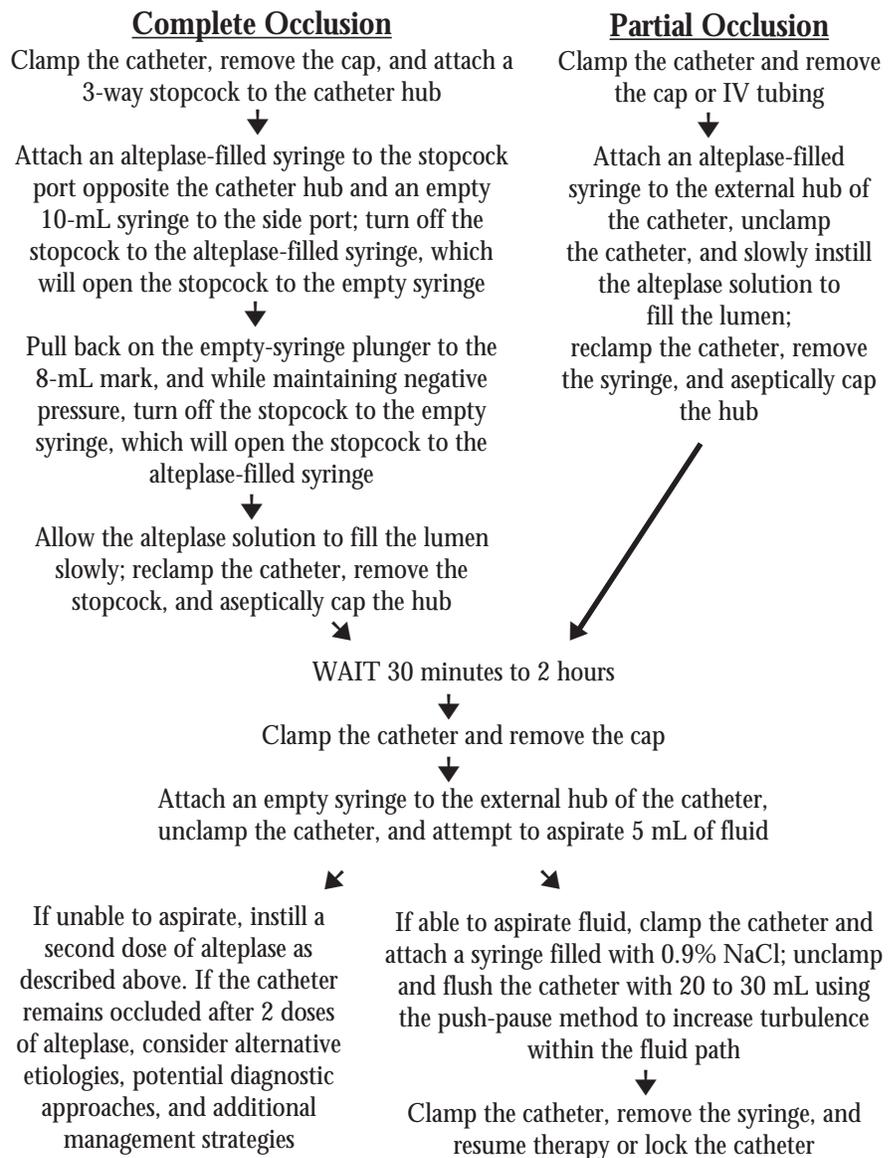
In summary, the studies of t-PA suggest that it is a well-tolerated and effective treatment to restore patency to thrombosed catheters. The consensus conference participants recommend that subsequent studies investigate other uses for t-PA, including prophylactic use to prevent catheter-related thrombotic occlusion and infection, and use with antibiotics to treat catheter-related infections. ☺

*Information from this article was adapted with permission from Gardiner-Caldwell SynerMed, the publisher of Clinician.*

**Bibliography**

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3. Maloney KW, Hillery CA, Nelson TJ, Gill JC. The use of aliquoted and frozen t-PA in central venous line occlusions. *Blood.* 1999;1(suppl):25a. Abstract 114-1.
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**Table 3. Suggested Procedure for Using t-PA**



*Adapted with permission of Gardiner-Caldwell SynerMed.*

**Table 4. Suggested Procedure for Aliquoting t-PA**

*Until t-PA is available in a catheter clearance dosage, institutions are aliquoting 50 mg doses into smaller doses and freezing them as indicated below. This process should be conducted under aseptic conditions in the pharmacy to minimize the potential for contamination since t-PA is preservative free.*

t-PA is available in powder form and should be reconstituted with preservative-free Sterile Water for Injection, USP to a concentration of 1 mg/mL. The solution is then aliquoted (typically 2 mL t-PA in 5- to 10-mL polypropylene syringes). It may then be used, or stored at -20°C for 1 month. To assure sterility, the t-PA should be thawed at room temperature and used within 8 hours.

## Recognize Your Favorite Consumer/Caregiver: Nominate them for an Oley Award.

Consumers, caregivers, even Regional Coordinators, love recognition. What a great way to tell them how much you admire their courage, perseverance, and willingness to help others in their struggle with homePEN. And who wouldn't appreciate a travel scholarship to the Oley conference in Milwaukee this summer? Or extra money for an educational program in their region?

### It's FREE and easy!

A simple form (inserted in this issue) with five, quick questions is all you need to complete. Technophiles can also find it on our website @ [www.wizvax.net/oleyfdn/nomform.html](http://www.wizvax.net/oleyfdn/nomform.html). Just type in your answers — fax it, mail it or click "submit" — and you're done. Send as many forms as you like.



**Any questions? See details below or call (800) 776-OLEY.**

#### Oley Foundation Child of the Year Award

- ★ 18 years of age and under
- ★ Home parenteral and/or enteral nutrition consumer
- ★ On homePEN for a minimum of three (3) years
- Winner will receive a travel grant to the Oley Conference in Milwaukee, Wisconsin, June 21 - 23, 2001

#### Mead Johnson Enteral Award

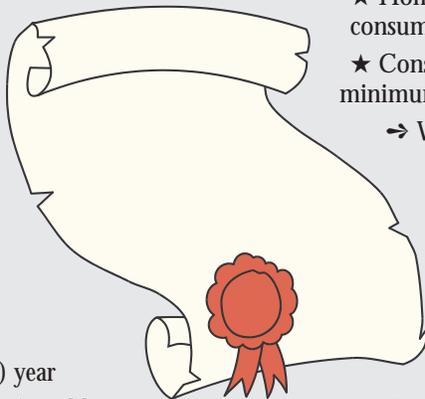
- ★ Enteral consumer, any age
- ★ On homeEN for a minimum of one (1) year
- ★ Resident of the Greater Milwaukee area (roughly 200 mile radius around the city)
- Winner will receive a travel grant to the Oley Conference in Milwaukee, Wisconsin, June 21 - 23, 2001

#### LifelineLetter Annual Award

- ★ 19 years of age or older
- ★ Home parenteral and/or enteral nutrition consumer or caregiver
- ★ Consumer has been on homePEN for a minimum of five (5) years
- Winner will receive a travel grant to the Oley Conference in Milwaukee, Wisconsin, June 21 - 23, 2001

#### Lenore Heaphey Award for Grassroots Education

- ★ Oley Foundation Regional Coordinator volunteer
- ★ Organized an outstanding information and/or education program during 2000
- Winner will receive a nominal cash award to foster educational/support activities in his or her local area



In addition to the award-specific criteria listed above, all nominees should demonstrate courage, perseverance, a positive attitude in dealing with their illness, and exceptional generosity in helping others in their struggle with homePEN. The awards will be given at the 16th Annual Oley Consumer/Clinician Conference to be held June 21 to 23, 2001 at the Hilton Milwaukee City Center, in Milwaukee, Wisconsin. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a special keepsake, are honored at the annual conference awards program and will be spotlighted in the *LifelineLetter*. Most awardees will have all or some of their travel expenses underwritten. Recognition is given to all nominees!

**Nominations must be submitted by April 2, 2001**

# 2001 Oley Regional Coordinator Listing

updated  
1/3/01

*Regional Coordinators are an integral part of the Oley Foundation's outreach efforts. To date, the following patients/caregivers have accepted these volunteer positions. If you need someone to speak with, or are interested in a get-together, contact the volunteer nearest you (even if he or she is not in your region). We encourage you to contact any or all of the others as they have an assortment of knowledge and experience to share.*

*To make speaking with fellow lifeliners more affordable, Oley also circulates two toll-free numbers to experienced HPEN consumers on a monthly basis. A schedule of the toll-free numbers is printed in the LifelineLetter. The toll-free schedule, and updated RC list, are also posted on our web page @ [www.oley.org](http://www.oley.org) or are available by calling the Oley office at (800) 776-6539.*

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*Don can also provide information on  
the Canadian Parenteral and En-  
teral Nutrition Assn. (CPENA)*

## Sufferin'? Succotash!

Tim Joyce, HPN Consumer

Every year the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) holds a Clinical Conference. This year the conference was held in my hometown, Chicago. During the conference, Oley conducts a session in which they introduce clinicians to the patient's and family's point of view. It was here that I finally put into words an idea that has been on my mind for some years.

One of the Oley panelists, Ann Weaver, is the mother of a six-year-old boy on homePN due to Hirschsprung's Disease. His doctors had given up on him at birth, and Ann gave up on the doctors. He now leads a relatively normal life, while she is probably a typical soccer mom. This was one of the points Ann found intriguing: "Why would they want me to give a speech about my normal life? Later on, Kathleen McInnes, an HEN consumer on the panel, also touched on this point.

### What Is Normal?

Perhaps you are now asking yourself, "What do they mean by 'normal'?" As consumers, we all know the problems we face day in, day out. We know we have to take time out of each day, maybe several times a day, to mix and hang or TPN or enteral formulas. The endless visits to the doctor, the catheter care and strange sleeping arrangements all make our lives very different from that of 'normal' people.

For those of you who are caregivers, you see and share in what we go through every day. Add to that the constant worry about your loved one's health. We know there are days when your ability to empathize has been used up and for two cents you could chuck it all. What could possibly be normal about this situation?

When the speakers broached the topic, I was reminded of a philosophy I've been thinking about for some time. I thought that here was an audience who might benefit by hearing it. I hope this meant something to those present and I hope it does to you.

I will, at a moment's notice, talk to anyone, anywhere, in whatever detail they can handle, about my various afflictions. I am not ashamed

of my catheter. Should someone ask about it, I'll tell them what it is and why I have it. When somebody asks me, "How ya' doin'?" I may tell them about my sore back or that I'm feeling tired. But I will never tell them that I *suffer* from Crohn's disease, aseptic necrosis, arthritis, pseudo-obstruction or any of the other maladies that afflict me. I no more suffer from these than I suffer from thinning hair.

### Living with a Condition

These things are simply conditions I live with. These disorders, all of them, and the challenges they present, have become common place for me. They are the background of my life. I didn't reach this conclusion overnight. It took six years from the time they sent me home with my first permanent line before I became fully at peace with my lot. Now I've learned to live my life around them.

After all, everybody has conditions they live with or, if you will, suffer from. So called normal people suffer from hunger and have to stop three times a day — interrupting whatever they are doing — in order to eat. I don't have to, although I can. We all suffer from the condition of sleep in which we must stop all activity and lose one third or more of our lives to unconsciousness. Normal people have to stop their lives to go to work. I don't have to work, although I can and sometimes do.

The point is: eating, sleeping and working are all normal activities around which we have created rituals — just as I have rituals for changing my dressing or hanging my bag.

If you're a patient, my sincere hope is that you are not feeling sorry for yourself. You need to get over it, and get on with living, loving and laughing. If you're a caregiver, doctor or whatever, don't see me as "suffering." I don't need nor want your pity. A little concern, however, along with a modicum of care and a friendly ear when I need it, will go a long way toward helping me meet the challenges of chronic illness.

So yes! I lead a normal life. In some ways my life is better than many 'normal' people. It is just a matter of perspective and experience. ☺



*Tim Joyce is a Regional Coordinator in Chicago, IL, who has 20 years experience with homePN.*

## PEN Pal Wanted

A woman from Indiana is seeking a supportive homePEN PEN Pal. She is on tube feeds and feels isolated and depressed. Send letters to:

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The following homePEN supplies are offered free of charge:

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For more information, call Roslyn Dahl at the Oley Foundation at (800) 776-OLEY/(518) 262-5079. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition.

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## Reach Out and Talk to a HomePEN Consumer — Toll Free!

*To make speaking with fellow lifeliners more affordable, Oley circulates two toll-free numbers to experienced homePEN consumers on a monthly basis. We strongly encourage you to take advantage of this program which enhances consumer-to-consumer networking and provides Regional Coordinators with a better grasp of their region's needs.*

*Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.*

*Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 15 minutes. The exception is **FRIDAYS, WHEN ALL CALLS ARE FREE** — including calls to the Oley office!*

*The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted on our web page @ [www.oley.org](http://www.oley.org). Comments? Call (800) 776-OLEY.*

<b>MAR. '01</b>	<p><b>Jane Golden</b> Watertown, CT (888) 610-3008 EST</p> <p><b>Mary Friel (NEW!)</b> Framingham, MA (888) 650-3290 EST</p>	<p>As a result of short bowel syndrome, Jane has been on and off TPN since 1993. She believes strongly in the benefits of networking with fellow lifeliners. Jane worked hard to get back to a "normal" life and until two years ago, worked full time for IBM. She enjoys horses and has a terrific sense of humor.</p> <p>Mary has been on TPN 7 years for short bowel syndrome due to Crohn's disease. She has attended two Oley conferences; works full time; is involved in many activities; and likes to travel. Mary has dealt with catheter infections, kidney stones and other complications from Crohn's. Call evenings or weekends.</p>
	<p><b>Malisa Matheny</b> Doylestown, PA (888) 610-3008 EST</p> <p><b>Sheila Messina</b> San Jose, CA (888) 650-3290 PST</p>	<p>An active young lifeliner and college student, Malisa is on HPN, and sometimes HEN, because of chronic intestinal pseudo-obstruction. She knows a great deal about summer camps that accept homePEN consumers. Upbeat and outgoing, Malisa enjoys networking with other lifeliners.</p> <p>Sheila has been on TPN for 15 years due to short bowel syndrome. She is an education and training specialist for case managers and has a lot of experience with managed care. She enjoys helping other lifeliners function as independently as possible and participate in their health care decisions.</p>
<b>MAY '01</b>	<p><b>Robin Lang</b> York, ME (888) 610-3008 EST</p> <p><b>Elizabeth Tucker</b> Bloomington, MN (888) 650-3290 CST</p>	<p>A TPN consumer for 21 years, Robin lives with her son and two dogs on 10 acres in Maine. She has traveled a lot (twice abroad) and worked prior to her recent application for SS disability. She loves to help others and make new friends. Robin keeps busy as a writer, Regional Coordinator and church volunteer.</p> <p>Liz has had Crohn's disease since 1965, and been on HPN since 1985. She can discuss her experience with Remicade, a newly-approved drug that battles Crohn's. Liz is very interested in health care and health insurance advocacy. She also has experience with a variety of stress management techniques.</p>

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*Nancy & Barbara Groat at the Oley Conference in Boston last summer.*