HOME NUTRITION SUPPORT RESOURCES
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From surgery to tube feeding to parenteral nutrition, Eileen Smith has been through a lot over the years, and has felt isolated from friends and family as a result. But thanks to two support groups — through the Oley Foundation and G-PACT — Eileen has found the support, comfort, and understanding to help her be strong and keep enjoying life.
In my case, in about 1983, it was a doctor at Massachusetts General Hospital who first suggested that home feedings, either by IV or a nasogastric tube, were in my future. At that time, it wasn’t easy to find sources of support. Not many groups existed that were dedicated to helping people on home nutrition. You found out about the resources that did exist through word-of-mouth or your doctor, if you were lucky.

The Oley Foundation, an education and support group for those on home TPN and enteral nutrition, was just starting up in the mid ‘80s. A few years before Clarence “Oley” Oldenburg and Dr. Lyn Howard founded Oley, Lee Koonin had founded the Lifeline Foundation to advocate for nutrition support consumers. Lee and her husband Marshall published newsletters and held events to bring consumers together. The Koonins eventually turned the Lifeline Foundation over to Oley. I knew about the Koonins because at the time they happened to live in my hometown of Sharon, Massachusetts.

But patients today have an advantage. There are so many more support groups available, and thanks to the Internet, it’s much easier to learn and connect with people who are going through the same thing that you are.

This issue of *Celebrate Life* shows many ways that support is available. It presents a variety of resources to help patients and caregivers cope with nutrition support therapy. We start off with an article from Lisa Metzger of the Oley Foundation and Traci Nagy of the Tube Feeding Awareness Foundation; the article tells you everything you need to know about these organizations. Another article, by Clinical Dietitian Sarah Allen, focuses on the ways people can connect online. Next, Nutrition Support Dietitian Barbara Spencer shares the inspiring story of Eileen Smith, which shows how Eileen marches on in the face of a chronic illness with the help of support groups that can “help ease our sense of isolation.”

Also in this issue, Mandy Corrigan, Nutrition Support Dietitian, writes about a variety of disease-specific organizations that not only enhance awareness, but also connect people through activities and support groups. And Karen Hamilton, Coram’s Director, Nutrition Services & Programs, writes about everything you need to know about finding the right support group for you.

There’s also information about Coram’s Nourish™ Nutrition Support program resources to help consumers lead better lives while they are going through their therapy. That includes the Nourish website, WeNourish.com, which includes print, audio, and video patient education resources, information on our Great Escapes™ Travel Program, and billing resources.

And I’m happy and proud to say, this issue also tells you all about me. I’m a new Patient Advocate at Coram, and you’ll find my story in the Advocacy Corner. I’m at Coram helping consumers know that they always have someone to talk to.

I’m honored to be the Guest Editor for this informative issue of *Celebrate Life*. Enjoy!
ON TPN OR TUBE FEEDING?

There’s a Resource for You!

By Lisa Metzger, Editor of LifelineLetter and Director, Community Engagement, Oley Foundation, and Traci Nagy, Founder and Executive Director, Tube Feeding Awareness Foundation
Home parenteral and enteral nutrition (HPEN) provides people with the nutrients they need to survive and grow. However, managing these therapies can sometimes seem overwhelming and isolating. Coupled with the fact that therapy-related complications can occur despite the best self-care, consumers can feel like they need a lifeline!

Therapy-specific support organizations can come to the rescue. They can help HPEN consumers live full, independent, and connected lives. These groups build on the education that consumers gain from their healthcare providers. They also offer social contact. The groups offer consumers the chance to meet others face-to-face. And, as HPEN consumers are spread across the U.S., the groups also offer robust social media opportunities. In short, these organizations help to lay a foundation of hope that consumers can use to grow stronger and more informed. This can help consumers to fully enjoy life and all it has to offer.

Two key groups that provide resources for nutrition support patients are the Oley Foundation and the Feeding Tube Awareness Foundation. This article highlights what each of these organizations can offer you.

The Oley Foundation
www.oley.org | 800.776.OLEY

One group that accomplishes the lofty goals described above is the Oley Foundation. The Oley Foundation is a national, independent, not-for-profit organization. It was established with private funding in 1983 by Lyn Howard, MD, and her patient, Clarence “Oley” Oldenburg. Their goal was to address the unique needs of patients and professionals involved in HPEN support. Today, the Oley Foundation has over 13,000 members.

Oley can be a lifeline for HPEN patients who need information or connection. It offers a range of outreach programs and resources. The benefits of being connected with Oley are shown in a 2002 National Institutes of Health (NIH) study that focused on home parenteral nutrition patients. The study found that patients who were affiliated with Oley had a lower rate of catheter-related infection, less depression, and a higher quality of life than patients who were not.*

Key Oley outreach programs include:
- **The Lifeline Letter**: This bimonthly newsletter is available in print and online. It offers medical information, personal stories, and patient-to-patient tips for managing HPEN. It also provides the latest research and news about all things related to HPEN.
- **Oley’s website**: This site offers a wealth of information on HPEN. Highlights include:
  - **MY HPN online learning modules**. These are interactive sessions with text, pictures, videos, and printable tip sheets. They help users learn more about self-advocacy in the healthcare system.
They also teach about catheter-associated infection, fluid balance, glucose control, and more.

» **Centers of Experience list.** This list includes medical centers across the U.S. and Canada that have experience managing HPEN and intestinal failure.

» **Forum.** In this lively online community, members share ideas, thoughts, and questions.

» **Resources.** These resources cover topics from the latest research on stoma and skin care to traveling with HPEN.

- **Conferences:** Hundreds of HPEN consumers, caregivers, clinicians, and industry representatives attend the annual Oley Consumer/Clinician Conference each year in June. For 2014, Oley is also planning several smaller, one-day sessions in different parts of the U.S. All Oley conferences include educational sessions. They also include time for attendees to socialize and share personal experiences.

- **Equipment-Supply Exchange:** Oley maintains a database of supplies and equipment donated by people who no longer need them. Oley helps get the supplies/equipment into the hands of those who do need them. They receive over 1,000 requests per month for these items.

- **Research and Advocacy:** Oley has supported research on several topics that impact HPEN consumers. These topics have included evaluating the risk of aluminum overload in long-term PN patients. They have also included assessing the amounts of micronutrients in PN, and measuring quality of life for HPEN patients.

To promote advocacy, Oley looks for ways to make the HPEN consumer’s voice heard. It addresses issues such as drug shortages and competitive bidding. It also works to spread awareness with other groups and governmental agencies. These include the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), the Digestive Disease National Coalition, and the Food and Drug Administration.

- **Oley Ambassador Network:** Over 60 HPEN consumers, parents, and caregivers serve as volunteers for this network. These volunteers reach out to and answer questions from other HPEN consumers, caregivers, and family members.

- **Useful Tools:** The Oley Foundation provides tools to encourage safe therapy administration practices. These tools include the HPN Complication Chart, the Tube Feeding Troubleshooting Guide, and the “Keep Me Safe” initiative.

**Feeding Tube Awareness Foundation**

[www.feedingtubeawareness.org](http://www.feedingtubeawareness.org)

The Feeding Tube Awareness Foundation (FTA) provides parents and caregivers with information needed for day-to-day life with a child who is tube-fed. They are a nonprofit, 100% volunteer organization. They strive to raise awareness so that tube-fed children enjoy increased acceptance in society, and their parents have greater support. Run by parents whose children are on daily tube feeding, the group strives to make complicated conditions and treatments easier to understand for other parents and caregivers. This group has a wide array of helpful resources and information, including:
• **Online resources:**
  
  » **Website.** FTA’s website includes video tutorials and inspiring patient and family stories. It also includes a very helpful section for friends and family members to help them understand what it is like to have a tube-fed child. In addition, the site features feeding pump manuals. These are available in multiple languages.
  
  » **Facebook.** FTA’s active Facebook page is an excellent resource for parents for information exchange and support. (www.facebook.com/FeedingTubeAwareness)
  
  » **Blog.** FTA’s blog provides useful information and ways to connect for parents of “tubies.” (www.feedingtubeawareness.com/AllThingsTubieBlog.html)

• **Educational resources:**
  
  » **Therapy-related information.** FTA provides information about formula coverage, including manufacturer resources. It also provides sample letters of medical necessity to demonstrate need, and details on patient assistance programs.
  
  » **Special education resources.** These resources can assist parents who have children with special needs. They help parents advocate for educational plan modifications and resource support.

• **Medical travel assistance:** These resources include information on charitable airline networks. They also include details on travel agencies that promote vacations that support the disabled.

• **Camps for kids with special needs:** These camps include medical specialty camps and camps for kids with serious illnesses.

• **Feeding Tube Awareness Week:** Since 2011, the group has hosted a campaign called “Feeding Tube Awareness Week.” The mission of this week is to promote the positive benefits of feeding tubes as a life-saving medical treatment. To do this, they invite parents and caregivers to share their stories through social media, blogging, tweets, and videos. Feeding Tube Awareness Week takes place each year in February.

Therapy-specific support organizations are a key resource for HPEN consumers. These groups can enhance your education about your therapy and provide you with essential connections with others who have had similar experiences. Through the many resources they provide, these groups can help you or your child live a full and independent life while receiving tube feeding therapy.


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*Therapy-specific support organizations help to lay a foundation of hope that consumers can use to grow stronger and more informed. This can help consumers to fully enjoy life and all it has to offer.*
CONNECTING WITH

THROUGH

DISEASE-SPECIFIC ORGANIZATIONS

By Mandy Corrigan, MPH, RD, LD, CNSC, FAND, Nutrition Support Dietitian
A variety of disease-specific organizations have resources for people with the same disease that you, a friend, or a loved one may have. Many of these organizations have members that require nutrition support therapies such as total parenteral nutrition (TPN) or enteral nutrition (EN). The goal of these organizations is to enhance awareness of the specific disease. These groups also provide patient education, as well as fundraising to support research that may result in better treatment or even a cure. Finally, these organizations strive to connect people through activities and support groups.

To help our home nutrition support consumers better navigate the world of disease-specific support groups, I have outlined some of the organizations that my consumers find helpful. In addition, the box on page 11 lists other organizations that may be useful to you. If you know of other groups that may be of interest to our consumers, please contact us. We are always looking to build our growing list of resources at: WeNourish.com/consumers/links.aspx.

**G-PACT**
[www.g-pact.org](http://www.g-pact.org)

G-PACT is a nonprofit, disease-focused organization. It offers services for patients or family members affected by gastroparesis or intestinal pseudo-obstruction. The founders of this group have a strong interest in helping others with these diseases. This is because they have experienced these diseases themselves (as either a patient or a caregiver). G-PACT offers:

- **Online support groups**: G-PACT offers a variety of support groups for people of a range of ages affected by gastroparesis or pseudo-obstruction.
  
  » These groups, which can be found at [www.g-pact.org/support.html](http://www.g-pact.org/support.html), provide support for a range of people. These include teens, parents, siblings, and caregivers. They also include consumers who are raising families, and those who have lost a family member or friend to gastroparesis or pseudo-obstruction.

- **Local connections**: G-PACT provides local in-person support groups to connect consumers face-to-face. Please email G-PACT directly at contact@g-pact.org for more information.

- **Patient Awareness Liaison Program (PAL)**: This program teams up volunteers who have gastroparesis or pseudo-obstruction with patients who also have one of these diseases. While PAL volunteers are not counselors, they do provide an over-the-phone live support connection. They can refer patients to available resources and answer basic questions using their experience and background.

**Mitochondrial Disease Action Committee (Mito)**
[www.mitoaction.org](http://www.mitoaction.org)

Mito is a nonprofit organization. Its vision is to create a community of support that reaches every child, adult, and caregiver affected by mitochondrial diseases. Mito offers detailed information to help understand mitochondrial disease and extensive support resources for living with the condition. Mito knows that a new diagnosis can be overwhelming. Because of this, it highlights an area of its website with resources to use as a starting point ([www.mitoaction.org/overview](http://www.mitoaction.org/overview)).

Connecting with other Mito consumers or families can be done in a variety of ways. Mito offers the following options for support:

- **Patient and family socials**: At these events, you can meet other consumers in person to give and receive support.

- **Online forums**: There is a large network of forums on the Mito website. They range from the general MitoAction forum to areas for fundraising, news, advocacy, medical questions, and many others.
Toll-free support number: 888.MITO.411

Summer camp programs: Mito offers kids with mitochondrial disease a week-long summer camp experience, free of charge.

Other resources: Beyond support groups, Mito offers resources for consumers and families to improve the quality of their daily lives. Mito also offers teleconferences, emergency room letters, weekly physician-led podcasts, and newsletters. In addition, they provide a wide range of resources to assist school-aged children attend school with a mitochondrial disease.

Short Bowel Syndrome Foundation (SBSF)
www.shortbowelfoundation.org

SBSF is a recently developed nonprofit organization designed for people with short bowel syndrome (SBS). The founder has first-hand knowledge of many aspects of the disease gained from living with SBS for many years. The mission of SBSF includes education, advocacy, and support.

SBSF offers three support groups:

- Short Bowel Syndrome Adult Support Group: This group is on Facebook at www.facebook.com/groups/sbsfoundationadults
- Short Gut Syndrome Parents Support Group: This group can be found on Facebook at www.facebook.com/groups/shortgutsupport
- Short Gut Syndrome Families’ Support Group: This is a pediatric support group available at www.shortgutsupport.com. This group includes a message board, support group meetings, and one-on-one support.

SBSF offers financial support through grants for SBS educational opportunities and a range of fundraising events. On their website, see consumer stories, review previous grant recipients’ profiles, and learn about fundraising opportunities that connect consumers and family members.

Crohn’s and Colitis Foundation of America (CCFA)
www.ccfa.org

CCFA is a nonprofit organization aimed at helping people with Crohn’s disease or ulcerative colitis. CCFA’s website is full of information to help you understand these conditions. It also provides information on educational programs, fundraising, research, and support.

CCFA offers support through an online community and face-to-face services.

- Online forums: These forums cover topics such as nutrition, medical treatments, wellness, parents/caregivers, and men’s and women’s issues. They also feature a special area for newly diagnosed patients.
• **Online support group:** This support group is led by a CCFA moderator and meets for 90 minutes each week for four weeks. The group focuses on allowing members to share their experiences and learn from those of others. It also helps members to build relationships with others who have the same disease.

• **Camp Oasis Summer Camp:** This camp is specifically designed for kids with Crohn’s disease or ulcerative colitis. It offers kids the chance to find strength in being with peers who have the same disease while participating in fun events.

• **Local chapters and local events:** The main CCFA website features an easy-to-use tool to help you find local support groups and events.

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**Scleroderma Society**

[www.scleroderma.org](http://www.scleroderma.org)

The Scleroderma Society is a non-profit organization established in 1998 for people with scleroderma and friends or family members of scleroderma patients.

The Scleroderma Society offers the following support resources:

• **Toll-free help line:** 800.722.4673

• **Support groups:** The organization lists support groups located across the country.

• **Online discussion boards:** These boards include a general discussion board, as well as boards for newly diagnosed and juvenile patients, and for family and friends of scleroderma patients. There are also boards that focus on the specific type of scleroderma a patient has. [www.inspire.com/groups/scleroderma-foundation](http://www.inspire.com/groups/scleroderma-foundation)

• **Local chapters:** The group has 24 local chapters across the U.S. These chapters have websites that feature links to social media connection options (Facebook, YouTube, Twitter, and Flickr).

• **Annual conference:** This meeting provides educational and networking opportunities with people who live with scleroderma.

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These are just a few examples of disease-specific organizations that offer support groups. Although each of the organizations focuses on a different disease state, each group is focused on fostering support through connecting its members. We hope this information helps you connect to others with whom you can share ideas and experiences!

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**Additional Resource Organizations for Home Nutrition Support Consumers**

- Association of Gastrointestinal Motility Disorders, Inc. [www.agmd-gimotility.org](http://www.agmd-gimotility.org)
- Celiac Disease Foundation [www.celiac.org](http://www.celiac.org)
- Ehlers-Danlos National Foundation [www.ednf.org](http://www.ednf.org)
- Hyperemesis Education & Research Foundation [www.hyperemesis.org](http://www.hyperemesis.org)
- International Foundation for Functional Gastrointestinal Disorders [www.iffgd.org](http://www.iffgd.org)
- United Mitochondrial Disease Foundation [www.umdf.org](http://www.umdf.org)
- United Ostomy Associations of America, Inc [www.uoaa.org](http://www.uoaa.org)

Please note that some organizations may charge a fee for access to services. This listing does not endorse these groups or information they may provide. We strongly suggest that you discuss any information you receive from these organizations with a qualified professional before making any changes in your healthcare, insurance coverage, or home care provider.
In August 2004, Eileen Smith was a busy wife and mother. She also enjoyed her job as a teacher’s assistant with autistic children.

One day, she and her fellow teachers went out for lunch at a Chinese restaurant. A few hours later, she began to vomit. Thinking it was food poisoning, she thought it would be over in a day or so. It was a turning point that would change every aspect of her life. It would also lead her to discover the helpful world of support groups.

By Barbara Spencer, RD, CNSC, Nutrition Support Dietitian
From Healthy to Emergency Surgery

Eileen vomited constantly for the next few weeks, which finally landed her in the emergency department (ED). She was diagnosed with gastric reflux* and was discharged home. Eileen continued to have abdominal pain that she describes as “horrific.” She returned to the ED the next day and was admitted to the hospital. Four days later, she went into septic shock,* which threatened her life. Eileen’s doctors tried to prepare the family for a grim outcome. They told her husband to bring their children to the hospital to say goodbye.

As a last-ditch effort, doctors performed emergency surgery. The procedure released adhesions* that had caused a complete small bowel obstruction.* Previously, Eileen had undergone three cesarean sections* and a hysterectomy.* Doctors believed that these procedures had caused scar tissue that led to the blockage. The scar tissue had created a barrier that kept bile* from flowing into the small intestine. Instead, the bile backed up into the stomach, making Eileen feel nauseous. Fortunately, Eileen survived the surgery. She looked forward to regaining her health at home.

Treatment, But No Solution

Eileen recovered from this ordeal, but continued to have vomiting. She later had a gastric emptying test* and was diagnosed with gastroparesis.* A motility* expert told Eileen that the bile had moved deep into her stomach tissues. The bile had destroyed her stomach’s ability to move digestive contents into the small intestine.

Eileen consulted motility experts from major hospitals who worked in gastrointestinal disorders. She tried a variety of motility drugs, but none worked. She tried changing her diet, but found that the only foods she could tolerate were protein shakes and yogurt. Eileen was losing a lot of weight, so her doctor recommended enteral nutrition.* A jejunostomy tube (J-tube)* was placed in an effort to help Eileen gain weight, but there were problems. The J-tube caused constant intestinal spasms and was very painful. Eileen also had other complications from the tube, including skin infections, and she kept losing weight. To prevent further malnutrition, a Hickman catheter* was placed and TPN* was started.

Eileen continued to vomit often and was very frustrated that her condition was not getting any better. Eileen’s doctors advised her to have a partial gastrectomy.* She was hopeful that this procedure would stop the vomiting, allow her to eat more, and improve her quality of life. However, the procedure was not effective. Sixteen months later, Eileen had a total gastrectomy to remove the rest of her stomach. This surgery was not helpful either. Unfortunately, Eileen is still having chronic nausea and vomiting.

Oley and G-PACT Make All the Difference

Eileen’s medical problems made her feel very isolated. Coworkers who had been close to Eileen stopped calling. Friends she had once relied on told her they “couldn’t deal” with her health problems.

So, Eileen took matters into her own hands — she went online to find a support group. She found the Oley Foundation.* Eileen posted a plea on the Oley website: “Anybody please help.” She quickly received a response from a woman in Atlanta, Georgia, who also had gastroparesis. To Eileen’s great delight, Oley provided her with a community of support from people all around the world.

Eileen notes that being a part of an organization with international members allows her to “turn to someone, even if it’s 3:00 in the morning!” Over the years, Eileen has formed friendships with six people across the U.S. “Having a chronic disease can be very isolating. The postings on Oley were so helpful — I learned so many things! Everyone was really caring. Without the Oley Foundation, I wouldn’t be where I am now.”

A natural leader, Eileen wanted to start a local group for people with gastroparesis and their families. She started by gathering useful information from G-PACT, a support group for people with gastroparesis. Eileen then posted an ad in a local newspaper. Four people showed up to the first meeting. Although these meetings waned with time, Eileen maintains a close friendship with one of the original members.
Moving Ahead with Life

As anyone with a chronic illness knows, life moves on despite health challenges. Being part of a support network for many years has let Eileen know that she is not alone in her situation. The connections she has made through her support community give her confidence. She knows that she can move forward and celebrate the milestones of life.

Eileen and her husband raised their family. A year ago, their oldest child announced that she would be moving across the country to live on another coast! Eileen wanted to be a part of this important change in her daughter’s life. On her first trip to the West Coast to visit her daughter, Eileen worked with her Coram Patient Advocate. Through the Great Escapes™ Travel Program,* she was able to travel smoothly between airports with her nutrition therapy, pump, and supplies.

Over the past year, Eileen has made this coast-to-coast trip several times. She is a strong person, and with the help of her support network and Great Escapes, she can now travel with confidence.

Eileen’s story is inspiring. Her message to other people with chronic illness is, “Try not to give up.” Eileen knows that chronic illness impacts every aspect of life, and even affects other family members. Over the years, she has learned that people have “different ways of coping, but there are still the daily struggles we all share. A support group is a powerful way to help ease our sense of isolation.” She says that with the special friends she met through Oley, G-PACT, and her local support group, she doesn’t feel alone anymore.

Wise Words from Eileen Smith

Many people battling a chronic illness feel very much alone. A support group is a place where we can find comfort, understanding, and a sense of belonging. Members of the group who have the same problems can support each other, and may suggest new ways of dealing with a particular problem. Support groups allow people with a difficult illness to openly share and communicate about what they are experiencing. I am glad that I was able to find a support group that allowed me to connect with so many like me. It gave me the support I needed, and it also allowed me to help others who were newly diagnosed.

With a support group, we have a bond that allows us to speak honestly with each other and not be judged or looked upon as a “hypochondriac” or complainer. The group can become our “friend/family” who responds to us very differently than our actual friend or family. It helps us emotionally, physically, and mentally.

*Glossary:

Adhesions: Bands of tissue fiber that form scar tissue. Adhesions often result from surgery or inflammation.

Bile: A fluid produced by the liver that helps to digest fats. Bile is stored in the gall bladder.

Cesarean section: Surgery in which a baby is delivered through an incision (cut) in the mother’s abdomen.

Enteral nutrition: A method of nutrition support. Nutrition is sent directly into the stomach or small bowel. This is done through a tube inserted into the nose, or through the wall of the abdomen.

Gastrectomy: A surgical procedure that removes part or all of the stomach.

Gastric emptying test: A test that measures the amount of time it takes for the stomach to empty its contents into the small intestine.

Gastric reflux: Backward flow of digestive fluids and food from the stomach into the esophagus.

Gastroparesis: Paralysis of the stomach muscles. This results in poor emptying of the stomach into the small intestine.

Great Escapes Travel Program: A service offered to Coram patients to help them travel with medically necessary liquids. Available in all 50 states, the Great Escapes program provides support services for those travelling on nutrition support. For more information, visit WeNourish.com/travel.

Hickman catheter: A central venous catheter used for long-term intravenous (IV) therapies.

Hysterectomy: Surgical removal of the uterus (womb).

Jejunostomy (J-tube): A feeding tube that is inserted through the abdomen into the second part of the small intestine (jejunum).

TPN (total parenteral nutrition): A method of nutrition support. Nutrition is sent into the bloodstream through an intravenous (IV) line. The digestive system is not used.

Motility: Movement of food through the gastrointestinal tract to allow for digestion. Motility is caused by contractions (squeezing movements) of the stomach and intestines.

Oley Foundation (www.oley.org): A nonprofit organization that provides information and support to patients who receive nutrition support. See page 5 for more information.

Septic shock: A life-threatening response to an infection that has spread throughout the bloodstream and tissues.

Small bowel obstruction: A complete or partial blockage in the small intestine that keeps food or liquid from passing through.
Finding a Support Group

By Karen Hamilton, MS, RD, CNSC, Director, Nutrition Services & Programs

What Is a Support Group?

Support groups are groups of people who share a common condition or interest. A support group lets you know that you are not alone, and that others understand what you are going through.

These groups serve many different needs. Some deal with broad-based issues such as problems with communication. Others may be more specific, such as with disease- or condition-based groups (see page 8). Support groups can be run by nonprofit organizations, health clinics, or other organizations. Some are initiated by an individual who has a health disorder, or has a family member with one.

Support group meetings can have a variety of formats, including in-person, on the Internet, or by telephone. Most health disorder support groups focus on a specific condition, such as Crohn’s disease or colitis, pseudo-obstruction, or scleroderma. Other support groups focus on the unique needs of consumers who receive specific therapies, such as home parenteral and enteral nutrition (tube feeding). Regardless of the format, members of a support group share their personal journey with their condition and share comfort, support, and advice based on their own experiences.

Most groups that are health disorder-based focus on ways to achieve goals and maintain positive changes. They also promote coping skills and provide emotional support. Perhaps one of the biggest benefits of joining a support group is that you meet people dealing with and surviving the same problem. This may help you know that you too can manage and thrive.

Benefits of a Support Group

- **Making connections.** Meeting others with a condition or need similar to yours can make you feel less alone or isolated.
- **Improving your coping skills.** Support groups offer the chance to draw on collective experiences. Others who have “been there” may have tips on coping with your condition that haven’t occurred to you. Brainstorming with others in the group might inspire even more ideas.
- **Getting motivated.** Joining a support group might encourage you to take a more active role in your treatment, or to stick to your treatment plan. And a support group may help you tap into community resources, such as transportation or financial assistance.
• **Finding hope.** Sharing experiences and making connections can help you feel better about life in general. Seeing others make strides despite their illness or condition can provide you with hope about your own future.

• **Supporting your supporter.** With your new-found hope and motivation, you may be able to give your caregiver some respite by sharing your issues with others. There are support groups for caregivers as well. This may be just what your loved one needs to “recharge” and be better able to care for you.

**Finding the Right Group**

Most support groups welcome new participants. Below are some tips on how to find one that deals with your specific needs:

- If you work, ask for referrals from your company’s employee assistance program.
- Check classified listings under meetings, support, or mental health.
- Look in the phone book under “Information and Referral,” or call your local United Way agency.
- Ask your doctor, pharmacist, or dietitian for recommendations.
- Check with the local or national association for your particular condition.
- Check with other community resources such as public libraries and places of worship.
- Visit WeNourish.com/consumer/links.aspx to find a comprehensive listing of support groups and resources.

Here are some things to consider when deciding on a support group:

- Is it geared toward my specific therapy, condition, or illness?
- Is the location or online format convenient for me? Does it allow me to participate regularly?
- What is the meeting schedule?
- Is there a facilitator or moderator?
- Is there a clinician/health expert involved with the group?
- Is it confidential?
- Does it have established ground rules?
- What is a typical meeting like?
- Is it free, and if not, what are the fees?
- Do other group members believe that this group has helped them?

**Before You Join**

Plan to attend a few support group meetings to see how you like the group. If the support group doesn’t feel right for you, or if you don’t find it useful, you can always try another one. Remember that support groups can change as people join and leave. Assess your support group from time to time to make sure it continues to meet your needs.

**Making a Commitment**

After you find a group, give it a good try. You might feel awkward at the first meeting, so attend at least a few before you decide whether the group can meet your needs. You will have more success if you become an active participant. Also, keep your expectations realistic, and support others as well as be supported.

**How Long Do I Need a Support Group?**

How long a person remains in a support group depends on their unique needs. There is no “right” length of time for any one person. Some leave when they feel that they have gotten everything they needed from the support group. Others may continue for years as they have made wonderful, supportive friends. Or, perhaps they want to continue so they can support new members. ♦

A support group lets you know that you are not alone, and that others understand what you are going through.
THE ONLINE WORLD: Bringing People Together

By Sarah A. Allen, MS, RD, LDN, Clinical Dietitian
Starting nutrition support can bring forth many emotions. You may feel alone. You may be scared of doing something wrong. You may even feel isolated from friends and family who do not understand what you’re going through. No matter how you feel, know that you are not alone. Whether you are on TPN (total parental nutrition) or enteral nutrition (tube feeding), every day thousands of Americans rely on the same home nutrition support therapy that you do.

Fortunately, online resources can help. These resources include social media, which has grown immensely in recent years. They also include message boards. By going online, you may be better able to connect with others on nutrition support than ever before.

Social Media
Social media refers to the creation, sharing, and/or exchange of information and ideas in online communities and networks. Social media sites are web pages that allow users to interact with each other. Most sites allow everyone who accesses the site to see the information that is posted. Others may require passwords. Postings may be limited to site members or user-selected individuals. Postings can include text, pictures, audio, or video, and other users can comment on the postings.

There are currently six main types of social media:
- Social networks,
- Microblogs,
- Blogs,
- Bookmarking sites,
- Social news sites, and
- Media sharing sites.

Some of these sites contain only one type of social media, while other sites contain a mix. Each type of social media is helpful in a different way.

Social Networks
With social networks, an individual or business creates a page that contains a profile and pictures. The user can invite other users to be their “friends,” creating a network. Each user can make public comments on their own page and friends can leave public comments for them. Private messages can also be sent between users.

Groups exist for users with the same interests. Nutrition support consumers can make use of social networks in many ways. For instance, users may post a comment asking what others have done to correct the same tube feeding problem. Or, they may inform friends about an upcoming fundraising event.

Examples of Social Networks
- Facebook (www.facebook.com)
  » My Mic-Key
  » The Oley Foundation
- Google+ (www.google.com/+)
  » The Feeding Tube Awareness Foundation

Being Safe on Social Media
Please be aware that anyone can post a comment online. And some comments, such as health advice, may not be accurate, or they may be misleading. Always consult your doctor before doing any troubleshooting or making changes to your health care.
Microblogs
Microblogging is similar to social networking in that each user creates a page with a profile and picture. However, instead of creating a network of friends, users create a network of followers. The user of each page writes comments, which can only contain a certain number of characters. A # symbol is used to identify the topic of the comment. This allows users to find comment threads on different topics. For example, a comment containing “#tubefeeding” would come up when a user searches for tubefeeding.

This type of social media is typically used to give quick updates. For instance, when Hannah’s Law was signed into law in October 2013, Twitter users posted links to articles discussing it. (Hannah’s Law requires New York insurance companies to cover enteral formula for children with eosinophilic esophagitis.)

Examples of Microblogs
- Twitter (www.twitter.com)
  - Jonah and the Whale (@JTWForg)
- Tumblr (www.tumblr.com)
  - Adventures of a Sick Girl

Blogs
Blogging can be compared to keeping an online journal. The owner of the blog (“blogger”) can post entries as often as they like. The posts can be with pictures or without, and as detailed or as general as the blogger wants. Bloggers often write about personal triumphs and failures. Blogs may include factual information (such as pump troubleshooting) or emotions (such as being excited about finding the right formula). Blogs can help the blogger feel connected to an online community. At the same time, they can inform the reader. Readers may choose to follow a blog, or may stumble upon a blog only once. Most bloggers have their blogs set up so that readers can comment.

Examples of Blogging Sites and Blogs
- Inspire (www.inspire.com)
  - Head and Neck Cancer Alliance
- Blogger (www.blogger.com — connected to www.google.com)
  - agirlandhertube.blogspot.com
- Wordpress (www.wordpress.com)
  - patriciaspage.wordpress.com
- Weebly (www.weebly.com)
  - theezelltwins.weebly.com/blog.html

Bookmarking Sites
A social bookmarking site allows users to save website links or pictures of things they like on their page. They could be considered “digital scrapbooks.” In addition to posting pictures, users can re-post news articles or write their own articles. Users then create a network of followers who can see the things they like. You could find “tube-friendly” Halloween costume ideas or discover why others have found TPN helpful.
Examples of Bookmarking Sites
- Pinterest (www.pinterest.com)
  » Cerebral Palsy Family Network
  » G-Tube Pads
- StumbleUpon (www.stumbleupon.com)
  » Thorn Tree Forum

Social News Sites
Social news sites allow anyone to post a story they have written about any topic. Story format is typically similar to the format of a newspaper article. A unique aspect of social news sites is that users vote on the articles. The articles with the most votes are featured on the website’s home page. Articles can be searched by topic or author. Users can follow their favorite authors and be alerted when they have posted new articles.

Social news sites are a good way to read about topics that may not be covered by mainstream news sources. For example, one author may compare J-tube belts, while another may discuss her experience with gastroparesis.

Examples of Social News Sites
- Reddit (www.reddit.com)
  » reddit.com/r/feedingtubeawareness
- Newsvine (www.newsvine.com)
  » Health

Media Sharing Sites
Media sharing sites allow users to publically share pictures, videos, or audio clips. Most sites focus on only one type of media. Users create a profile on their home page, and then post as much content as they like. As with social media sites, users can search for media by topic or by who posted it. Users can also vote on media they like, with the most popular being featured on the website’s home page. Most sites also allow users to leave comments about the content. Media sharing sites are great for learning how to do something. For instance, you may learn how to give a bolus feeding or how to pack a feeding pump into a backpack.

Examples of Media Sharing Sites
- YouTube (www.youtube.com)
  » My MIC-KEY Tube
- Vine (https://vine.co)
  » Matthew Weinstein
- Vimeo (https://vimeo.com):
  » American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.)

Online Message Boards
Message boards are another type of interactive online service. These forums differ from social media. This is because even though the public is free to post comments, the site is run by one group or person. (For example, this is different from how a social network is managed, such as Facebook. Facebook runs the site, but individuals or other organizations create their own pages on it.)

Online message boards allow users to discuss a topic by posting questions and answers. Most sites require users to register with a username and password. On a message board, one user starts the conversation (“thread”) by posting a comment or question. Other users then post comments in response to the original post, or in response to follow-up posts. Posts can be long and detailed or short and to the point. Posts are monitored by the site, and inappropriate posts are removed.

Examples of Message Boards
- Nestle’s parEnTalk (www.parentalk.com/forum)
- CancerCompass (www.cancercompass.com/message-board.htm)
- WebMD (http://exchanges.webmd.com/webmd-exchanges/moderated-exchanges)

Online resources have made people around the world as close as neighbors. So what are you waiting for? It’s a small world and you’re not alone — it’s time to get online, make some friends, and share some ideas!

References
Nourish® Resources

Coram is proud to provide so many great resources for you, our home nutrition support consumers. These resources can improve your therapy experience and help you achieve the quality of life you desire.

Below are the top resources our consumers use to enhance their home nutrition support experience. These resources are a free service to our consumers. You can access them online, or simply contact your Coram Dietitian.

Patient Education Resources
Our website features multimedia home parenteral and tube feeding educational tools. These tools can help you get the most out of your nutrition support therapy.

WeNourish.com/consumers/education
• Print materials in English and Spanish
• Audio tutorials
• Video tutorials that can be viewed from your computer, tablet, or smart phone

Travel Resources
Our Great Escapes™ Travel Program helps consumers travel safely with their nutrition support therapy. We can support you whether your trip takes you across the U.S. or around the globe!

WeNourish.com/travel
• Your Passport to Successful Travel resource guide
  » Contains helpful tips on planning, packing, and traveling with your nutrition therapy
  » Provides Transportation Security Administration (TSA) travel guidelines
• Rolling cooler, with a video on how to pack the cooler
  » Keeps TPN supplies cool and close at hand while you travel
  » Coram Liaison who works with the Transportation Security Administration (TSA)
    » Helps ensure a smooth airport screening process for your medically necessary liquids
• Cory the parrot, our travel mascot
  » Includes a plush Cory to keep you company on your travels
  » Also includes a Cory tag to help you identify your luggage

Advocacy
Our advocacy program can connect you with resources and provide additional support. It can also help ensure that you are completely satisfied with your Coram care and service.

• Nourish Advocate and Patient Relations Specialist Team
• To contact your Nourish Patient Advocate:
  » Call toll-free 847.553.2998, mailbox #4042804 and leave a message, or
  » Email michael.medwar@coramhc.com

Billing Resources
At Coram, we have an entire team dedicated to making billing for your nutrition therapy as smooth as possible. Our goal is to maximize your benefit and reduce your out-of-pocket expenses. If you have questions regarding your statement, contact your Coram Dietitian. He or she will be happy to assist you.
We are so pleased to introduce Michael Medwar, our Nourish Program’s new Patient Advocate. He is well-qualified for this important position, as he has been providing help and support for people for as long as he can remember.

A BORN ADVOCATE
Michael, who lives in Massachusetts but services patients across the country, learned a long time ago how to support his younger brother. Gregory was born with a severe developmental disability. From explaining Gregory’s needs to home health aides to attending meetings regarding his care, Michael was always there for his late brother.

“I advocated for Gregory for years. He was such a joy, despite his physical problems,” says Michael. “He needed someone to speak up and care for him in every way. I learned a lot growing up with him and helping meet his needs.”

In addition to advocating for his brother, Michael learned to advocate for himself and others on nutrition support. He was diagnosed with Crohn’s disease* when he was nine years old, and knows first-hand what it’s like to be on nutrition support. Over the years, Michael went through periods on total parenteral nutrition (TPN) in the hospital and at home. This helped him become comfortable talking to doctors, nurses, and infusion company staff about his treatment. Michael was also on tube feeding at one point for six months. He went off of TPN for a while after he had surgery as a teenager, but his Crohn’s flared up again and he went back on TPN for 14 years. He discontinued TPN when the disease quieted down and he learned diet strategies to help him manage his condition.

Michael put all of this experience to use in high school when he began to advocate publicly. He and his mother, Joan — who was diagnosed with Crohn’s disease two years after Michael was — helped to pass a Massachusetts law in 1987. The law requires insurance companies to provide benefits for enteral (tube feeding) formulas for people with Crohn’s disease and ulcerative colitis.* “We both testified and attended the bill signing at the State House in Boston with Governor Michael Dukakis,” says Michael.

LEARNING ABOUT COMMUNITY
Michael learned even more about the world of nutrition support by getting involved in the community.

When he was a teen, his mother found out about the Oley Foundation.* She and his father, Eli, had to drag Michael to his first Oley conference, but as it turned out, the meeting changed his whole outlook.

“I was a sick teenager who didn’t want to travel and meet people — but it was a wonderful experience!” says Michael.

At that first conference, the Oley staff made him feel welcome, and he was happy to meet other people who could relate to being on TPN. He also had fun at the conference picnic and was excited to learn about the history of TPN and see new things, such as a portable pump.
“We went to many of the early conferences, and I’ve been to every conference since 2000. Even though I’m not on TPN anymore, I still have Crohn’s, and there is plenty I can still learn at the conferences. Plus at the conferences, I get to see my friends and find out how they’re doing. Over the years I’ve met so many wonderful people — other consumers, people involved with Oley, people who work for home care companies. I go way back with lots of great people from Coram.”

AN IDEAL OPPORTUNITY

Michael also knew Coram staff from his time as a Coram patient. In fact, it was a Coram nurse whom he had known since he was 17 who told Michael about his current Patient Advocate position. Michael was interested right away. The position would require listening to patients, understanding what they’re going through, and researching problems to help resolve them. He quickly realized that it was a great match for him.

“I thought this would be a perfect way to use my skills to help people,” says Michael. “I enjoy interacting with people, and I know a lot of nutrition support consumers. I’m always interested to hear what others are going through.

“Empathy is a big part of this position. You need to be able to put yourself in the consumer’s shoes when listening to them and think — how would that affect me, how would I want to be helped? Consumers want someone who really cares about what they’re going through. With my experience, that is easy for me. I can relate to how sometimes you need someone who can listen and make you feel like you really are cared for.”

But those aren’t the only skills Michael brings to the job. He also brings those he has acquired over the years in his work as a newspaper reporter and copy editor. “I can use my investigative skills on problems that need research. I can use my critical thinking and communication skills to look at problems and help people get to the bottom of them. I’ve used those skills my whole professional life.”

As if these skills and experience weren’t enough, Michael was a Board of Trustees member of the Oley Foundation from 2003 to 2010. He also served on two occasions as a co-chair for Oley’s annual conferences. And he is currently a Board member of the Sustain Executive Council for the American Society of Parenteral and Enteral Nutrition (A.S.P.E.N.).

WISE WORDS FROM SOMEONE WHO KNOWS

Michael clearly knows a lot about living with nutrition support. When asked what words of wisdom he would share with Coram’s consumers, he replied thoughtfully. “My philosophy has always been to enjoy the good days to the fullest, and when you have a bad day, just get through it. Try to appreciate that if you’re on this therapy, it can help you participate in and enjoy life. And if you have some hard times in the beginning, tell yourself that things will keep getting better.”

Michael is available to all of Coram’s nutrition support patients, whether on TPN or tube feeding. If you have a question or would just like to speak to Michael, he would love to hear from you. You can contact him at:

• michael.medwar@coramhc.com
• P: 832.296.7188

*Glossary

- **Crohn’s disease**: A chronic inflammatory disease that can occur throughout the digestive tract.
- **Oley Foundation** (www.oley.org): A nonprofit organization that provides information and support to patients receiving nutrition support. For more information, see page 5.
- **Ulcerative colitis**: An inflammatory bowel disease that affects the large intestine.
Consumer Contacts

Celebrate Life Magazine
To submit stories, comments, and suggestions for Celebrate Life, email: celebratelifecoramhc.com

Celebrate Life Subscriptions
Manage your subscription online at: WeNourish.com/subscription
- Update your contact information
- Go green! Sign up to receive Celebrate Life via email. The latest issue will be delivered right to your inbox.

WeNourish.com
- General information about the Nourish Nutrition Support Program
- Educational tutorials, videos and downloadable patient education tools
- Consumer events and teleconferences
- Online archive of Celebrate Life magazine
- Consumer resource links
- Local Coram branch maps and information

877.WeNourish (877.936.6874)
Call to speak to a TPN or tube feeding representative.

Nourish Advocacy Line
To reach a dedicated Consumer Advocate, call:
Toll-free 866.446.6373

Consumer Connect Conference Call Series
To view a schedule of upcoming conference call topics and times, visit:
WeNourish.com/events

Connect With Us

Nourish and Celebrate Life are services of CORAM CVS/specialty infusion services