Coping Well with Home Enteral Nutrition

Words of wisdom from resilient adult consumers

by

Cheryl W. Thompson, PhD, RD, CNSD
Preface

The purpose of this manual is to help adults living on home enteral nutrition (HEN) learn to cope more effectively with their therapy. Resilient individuals who have learned to adapt and ultimately thrive with HEN provided advice, encouragement and strategies to help others expand their own HEN-related coping skills.

This educational resource provides general information and strategies intended to enhance coping and should not be interpreted as professional advice or a substitute for medical counseling. Rather than trying to read the manual in its entirety, read one or two strategies each day. Always remember to talk with your health-care provider before considering potential treatment options or making changes to your HEN regimen. Although many resources and organizations are listed in this manual, this does not constitute an endorsement of any organization, educational resource, or self-help method. It is the responsibility of the reader to decide whether the information is appropriate for his/her needs.

This manual may be reprinted for educational purposes and is available at http://www.copingwell.com.

Glossary

« ACT » stands for A Coping Tip, which highlights examples of how you could turn the suggested coping strategy into action.

Health-care provider – refers to credentialed health-care professionals (i.e., physicians, nurse practitioners, physician assistants, nurses, dietitians and pharmacists).

Quotes from HEN consumers are included to share insights in their own words.

A special thanks

I would like to thank the HEN consumers who shared their insights with me. Without their wisdom and altruism, the development of this manual would not have been possible. I am also grateful for the staff at The Oley Foundation, Apria Healthcare and Coram Healthcare who assisted with recruiting participants for my doctoral research, which provided the foundation for this manual, and for the funding provided by the Utah Dietetic Association and Intermountain Healthcare.

Cheryl W. Thompson, PhD, RD, CNSD
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Strategy 1
Realize that you are not alone

Although each person’s experience is unique, consumers face many common challenges as they adjust to life with home enteral nutrition (HEN). This manual highlights how a group of adult HEN consumers learned to cope with the burdens they face, including those listed below. As you read this list, put a check mark by any of the problems you are experiencing or write other concerns. Realize that you are not alone. Begin to cope more successfully by reading this manual and discussing your concerns with your health-care provider.

1. ____ Unpleasant emotions (i.e., anger, blame, confusion, denial, depression, embarrassment, fear, frustration, isolation or self-pity)
2. ____ Inadequate HEN education, follow-up care or resources
3. ____ Loss of pleasures associated with food
4. ____ Gastrointestinal complications (i.e., nausea, vomiting, diarrhea, constipation, bloating, heartburn or reflux)
5. ____ Problems with tube placement or replacement; clogging or falling out
6. ____ Unintentional weight loss or gain
7. ____ Inflexible HEN schedule or a regimen that does not fit your lifestyle
8. ____ Altered relationships with family and friends due to HEN
9. ____ Social isolation
10. ____ Challenges when traveling
11. ____ Financial burden of HEN
12. ____ Negative body image (i.e., feeling self-conscious because of the feeding tube)
13. ____ Skin care issues at the tube insertion site (i.e., a poorly healing wound, infection, granulation tissue, leaking around the tube)
14. ____ Health-care provider lacks expertise in HEN-related problems
15. ____ Other: ________________________________
                                ________________________________
                                ________________________________
Strategy 2
Recognize that coping includes ups and downs

Coping successfully with HEN does not “just happen.” Some HEN consumers adapt quickly so that HEN becomes a manageable routine. Yet others might struggle for months or even years before describing themselves as having “bounced back.” No matter how long you have required HEN, you can still improve your ability to cope. Read further to learn how.

Some days will be better than others

You will likely experience fluctuations in your ability to cope with new and ongoing challenges. When you are going through a difficult period, it can seem as if problems will continue indefinitely, or that your entire life is affected. If you are having a bad day, it helps to remember that you have good days, too. Over time, you may find that some problems are only temporary setbacks or that some days are just better than other days.

« ACT »

Keep a journal to record your good days and accomplishments. When you are having a “bad day,” reading what you wrote can be an uplifting reminder of the good times and help you recall the overall progress you have made.

“Even though you might have a bad day, you don’t have them every day… it’s just a cycle.”

After four daily home health visits, one consumer said, “I started to do it [HEN] myself and it was no problem.”

“One of the doctors told me it was critical to keep a journal… he said, ‘write down when you’re having a good day’… because you realize you have more good times than you might sometimes realize.”

“When you don’t see any measurable improvement it’s hard to keep going. Yet, part of measuring your improvement is recognizing that you may take two steps forward but you may also have two steps backward. You have to look for progress over a period of time. You can’t expect day-to-day improvement.”
Strategy 3
Don’t dwell on problems… contemplate solutions

At times, you may feel as if your life revolves around the day-to-day activities of HEN – and your thoughts become filled with the negative aspects of your therapy. Reflecting on your problems should serve the important purpose of identifying possible solutions. However, dwelling on negative experiences without trying to resolve them can be self-defeating since these bad feelings are prone to become exaggerated or prolonged.

« ACT »

- First, become aware of your thoughts. Learn to stop dwelling on the past or unsolvable problems and start contemplating possible solutions to situations that you can change.
- When you find yourself focusing on the daily hassles of HEN, shift your attention to embrace thoughts that promote wellness and recovery.
- A statement written by Drs. Montgomery and Morris can help to lessen unpleasant feelings (1). “I expect some bad feelings in this situation, but I’ll cope; I won’t deny my feelings, but I also won’t dwell on them; if possible, I’ll do something constructive to improve this situation now; if not, I’ll do something else, pleasant or constructive to distract me.”
- When you are feeling blue, it can be especially difficult to think of ways to lift your spirits. Plan for times when your mood is low by preparing a list of activities to help distract yourself or identify constructive and enjoyable activities you could pursue.

One consumer described not coping with HEN as when “One minor daily challenge after another is viewed as a burden.”

One woman stated, “It’s alright to hate HEN at times even though it’s a needed help.” She received the following advice that she found helpful: “It was O.K. for me to hate my tube, or pity myself, just don’t stay in that position. You can have an hour or a day, then get back up and get over it. Don’t let it obsess you. You have to pull yourself out of it. I think mentally I have to say, ‘get busy and get over this.’ If someone tells me ‘don’t feel sorry for myself’ or ‘you shouldn’t be down and out,’ that makes it worse. You have to get it out, whether you talk to yourself or someone else.”
Strategy 4
Take charge

Health-care providers often need to make highly technical and emergent medical decisions without consulting the patient. In contrast, managing HEN requires you to make many day-to-day health-care decisions. Therefore, you are in charge of choosing the thoughts and actions that ultimately determine how well you adapt to life with HEN.

Think of HEN as a team effort

In some ways, managing HEN is like playing football — with you playing quarterback (not the ball)! Your teammates are family members and supportive friends, and your health-care provider is the coach. Just as great quarterbacks are not born with the skills they require, you must learn to become a skilled consumer. Quarterbacks fumble and get tackled, similar to consumers being faced with unexpected challenges. Nonetheless, you must pick yourself up and get back into the game. Like replacing an injured quarterback, there may be times when you are unable to make your own health-care decisions and must rely on a family member or trusted friend to serve as your advocate and make health-care decisions on your behalf.

« ACT »
- Although managing HEN is a team effort, you are ultimately responsible to lead the action and make repeated efforts to get back into the game. Assume the attitude of someone who is “in charge” and take actions that will lead to success.
- Appoint a durable power of attorney to assure that medical decisions made on your behalf are consistent with your wishes in the event you are unable to make them for yourself.

Recognize that you have a choice

HEN consumers can feel a loss of control over many aspects of their lives. At times, you may think you have “no choice” or that your options seem like choosing between the lesser of two evils. Nevertheless, only you have the ability to choose how you respond to a situation. Your thoughts and actions result in consequences, even if you decide not to do anything. With time and practice, you can choose ways of responding to a problem that are more constructive and regain a feeling of control.

« ACT »
- Refuse to play the role of the victim. Empower yourself by choosing to respond in a constructive manner. You will begin to see that there is a relationship between the thoughts and actions you choose, and your ability to cope with HEN.
Strategy 5
Knowledge is empowering... be informed

Teach Yourself

Being informed can help you 1) reduce uncertainty, 2) prevent and solve problems, 3) locate helpful products, 4) communicate more effectively with your health-care provider, 5) make informed decisions, and 6) regain some element of control.

Adapting to life with HEN will be easier if you have a thorough knowledge about HEN, or at least know where to find the information. Your health-care provider can be a valuable source of information; however, you may also need to rely on being self-taught.

« ACT »

To teach yourself, begin by finding sources of information that are current and accurate. Medical libraries at universities and hospitals are typically open to the public and offer a consumer-health section. Public libraries also offer valuable resources. Ask the librarian to help you find the information you are seeking. Strategy 29 lists additional resources from health organizations and reliable Web sites.

Share in decision-making

To become more involved in the process of making medical decisions, you and your health-care provider must both work toward a partnership of shared decision-making. As you put forth the effort to learn about HEN, you will become increasingly confident in your ability to make informed decisions and willing to share in the responsibility. Of equal importance, your health-care provider must relinquish sole authority in certain situations and help you become educated about preventive and treatment options.

« ACT »

• Choose a medical outcome that you and your health-care provider think is realistic to achieve. For example, you might work toward reducing your infusion time or having fewer episodes of nausea or diarrhea. Discuss treatment options including the potential risks and benefits, and what outcome is realistic to expect. Then, agree on the best way to proceed.

• Your desire to be informed about HEN and to participate in making medical decisions may vary at times. Participate in medical decisions to the extent you feel comfortable. Tell your health-care provider if you would like more involvement and show your willingness to learn.

“Empower yourself to be able to make some decisions for yourself, and then be smart enough to know when it’s working and when it’s not working. It gives you back the sense that you’re in control of what’s going on.”

“Medically, our society is very paternalistic, and it is very tempting when you are sick to want someone else to figure it all out for you.”
Strategy 6
Communicate effectively with your health-care provider

Plan ahead
Too frequently, consumers leave a medical appointment feeling dissatisfied because their health-care provider did not address all of their concerns. Be prepared to maximize the time you spend with your health-care provider.

« ACT »
• Write down your questions and list them in order of greatest concern. Do not wait until the end of your appointment to mention them. Alternatively, give the list to your health-care provider at the beginning of the appointment.
• Record any symptoms you are experiencing. If possible, include events that seemed to trigger them (such as a recent change in medication or formula).
• When you schedule an appointment, ask how much time you will have with your health-care provider. If you think you will need more time to discuss your concerns, ask if additional time is available.
• Use concise statements to convey your point.
• Learn as much as you can about HEN to gain the most benefit from your discussion with a health-care provider.
• If there is any literature you wish to discuss, bring a copy or provide the source of the literature to enable your health-care provider to evaluate the information more objectively with you.
• Tell your health-care provider if you doubt you will be able to follow the regimen he/she recommends. Use a simple, objective statement such as, “I do not think I will be able to follow those instructions because…” An open discussion can identify alternatives or at least increase your awareness of the importance of following your health-care provider’s advice.

Break the ice
Your health-care provider may not be aware of all of your medical needs or concerns, or the seriousness of your HEN-related problems, unless you mention them. Consumers are often reluctant to bring up sensitive topics such as mental-health concerns, memory problems or sexual dysfunction. Nevertheless, your health-care provider is trained to deal with sensitive issues and to assure confidentiality.

« ACT »
• Do not feel embarrassed discussing personal concerns or requesting services from a mental-health professional.
• Learn to speak up. Don’t try to second guess which symptoms are worthy of mentioning.
Be sure you understood correctly

Effective communication is a two-way street. Consumers often have difficulty understanding the medical terms and technical jargon used by healthcare providers. Additional obstacles to good communication may include impaired hearing, a rushed appointment, or language barriers. Furthermore, different healthcare providers may have given you seemingly contradictory instructions or advice, or you may have read conflicting medical information. It is your responsibility to ask your healthcare provider to clarify confusing information and assure you understood correctly.

« ACT »

• Ask your healthcare provider to explain any unfamiliar medical terms. Tell him/her if you do not fully understand any information or instructions.
• Restate what you heard to confirm that the information was explained adequately. Then ask, “Have I understood all of the information correctly?”
• Ask your healthcare provider to clarify what is the best medical advice to follow — and explain if the conflicting information is just personal preference or if one method is superior.

Communicate electronically

For some HEN consumers, e-mail is an effective way to communicate with their healthcare provider to schedule an appointment, refill a prescription, inquire about a bill, ask a question or let the healthcare provider know how they are doing. Although e-mail is not a substitute for an office visit, there are times when e-mail might be useful to supplement or clarify information.

« ACT »

Ask your healthcare provider if he/she is willing to communicate via e-mail. Some basic tips can improve this method of communication (2):

• Do not use e-mail to send an urgent message or confidential information.
• Make your topic clear in the subject line (such as “prescription refill” or “billing question”).
• State your message clearly. Be concise, yet provide adequate detail.
• Ask if an automatic “out-of-office” reply will be generated when your healthcare provider is unavailable.
Strategy 7
Master HEN skills

Some people learn a new HEN skill easily or remain motivated until they have mastered it. In general, people are more likely to keep trying until they succeed if they:
1) believe they have the knowledge and skills necessary to accomplish the job, and
2) think their success was the result of their own efforts rather than outside forces, such as fate or luck. Use the following tips to help you remain motivated to master HEN-related skills.

Use a series of small steps
One way to master a complex task is to break it down into a series of manageable steps.

« ACT »
Start by learning the first or most basic step. Practice until you can consistently do it right before progressing to the next step. Once you have mastered all of the essential steps, you can expect to accomplish the entire task successfully because it is just a series of manageable steps.

Learn from other HEN consumers
Speaking with other HEN consumers can be a highly effective way to learn practical information and skills.

« ACT »
Contact the Oley Foundation, an education and support group for HEN consumers (see Resources), or ask your health-care provider if he/she knows another HEN consumer that might be willing to serve as your mentor by answering questions via telephone or e-mail.

See one, do one, teach one
Whenever possible, ask your instructor to teach you using the see one, do one, teach one method used in educating health-care providers.

« ACT »
See one: Observe a health-care provider perform the task.
Do one: Perform the task while receiving feedback from the instructor. Ask for specific feedback to learn if there are areas where you could improve.
Teach one: Teach someone else the skill you learned. Although this phase is rarely included in consumer education, it can be a very effective way to reinforce what you have learned and enhance your mastery of the task.
Strategy 8
Gain control over your health care

Seek help from medical specialists
Medical care has become too complex to expect one professional to provide all of your health-care needs. In addition, finding health-care providers experienced in the needs of HEN consumers can be challenging. Do not hesitate to seek the services of professionals who specialize in:

- Skin and wound care — Wound, Ostomy, and Continence Nurses; and Enterostomal Therapists
- Nutrition — Registered Dietitians
- Mental health — Psychiatrists and Psychologists
- Medications — Pharmacists
- Physical strength and flexibility — Physical Therapists
- Activities of daily living — Occupational Therapists
- Swallowing disorders — Speech Therapists

« ACT »
Ask your primary health-care provider for a referral or contact the profession’s national organization (see Resources) to find a local expert.

Seek new or innovative equipment
Medical products and supplies are constantly being improved (such as feeding tubes and pumps, skin-care products, enteral formulas and medications). In addition, new therapies are continually becoming available (such as electrical stimulation to help some people regain the ability to swallow or to help their stomach to empty). The trick is finding out about them and deciding which would be best for you based on their relative risks and benefits. Remember: not every product or treatment works for everyone; professional advice and experimentation can help you find what works best for you.

« ACT »
- Contact a variety of resources. Ask an experienced health-care provider what HEN products he/she would (or would not) recommend and discuss their relative advantages and disadvantages. Contact a support organization to learn practical information about products and supplies; or access product information from company representatives and reliable online sources (see Resources).
Be prepared

No one wants to hear about potential side effects and complications. However, planning for the worst while hoping for the best can help you learn how to prevent or minimize potential HEN-related complications.

« ACT »

- Ask a health-care provider what you should and should not do if an unexpected complication arises.
- Obtain preprinted information from home-care companies, enteral formula manufacturers, or The Oley Foundation. Important topics include:
  - Gastrointestinal side effects: nausea, vomiting, diarrhea, constipation, or heartburn
  - Occlusion (clogging) or accidental removal of your feeding tube
  - Redness, tenderness, unusual leakage, or excessive tissue formation (called granulation tissue) at tube-insertion site
- All feeding tubes eventually need to be replaced. Ask your health-care provider to estimate how often you should replace your feeding tube and be alert for signs the tube is deteriorating. Always keep a spare feeding tube (and the instructions) available because you may need to replace it unexpectedly.

Get organized

Written documentation of your medical and nutrition history can be invaluable if you require emergency care or services from a health-care provider who is unfamiliar with your special needs. Develop a system that is convenient to record and update the information. Keep a copy of the information handy and bring it to medical appointments and when traveling.

« ACT »

- Document your important medical and nutrition information such as:
  - HEN infusion: time, duration, method and total volume infused per day
  - Enteral formula (brand) and use of any additives or dietary supplements
  - Water: bolus/flush amount and frequency
  - Feeding tube: type, brand and date of last insertion
  - Skin care — special supplies or procedures
  - Ability to eat and any dietary restrictions
  - Diagnoses, previous surgeries and therapies
  - Medications including dosage and allergies
  - Height, weight and history of weight change
- The Oley Foundation has developed sample forms that HEN consumers can fill out entitled “Packet for Travel and Hospital Admissions” (see Resources).
Consider an ounce (or two) of prevention

Coping successfully with HEN also involves preventive health habits: assuring adequate sleep, regular exercise, adequate nutrition and obtaining preventive medical services.

« ACT »

• Adopt preventive health habits to maximize your overall health and help you cope mentally and physically with HEN. List a healthy habit you would like to improve and at least one way to make progress:

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• Monitoring your health status can also be a preventive measure to assure timely intervention if needed.

“Remember, a feeding tube is never a total answer. It is only one of many facets of good health, including good/proper nutrition, proper medication, challenging exercise (including walking), a sense of humor, a positive attitude about life, avoidance of infection, a good support system in the family, and if one is so disposed, the blessings of a higher power.”
Strategy 9  
Focus on physical recovery first

Regain physical strength and replete nutrient stores

Some consumers are physically weakened or have suffered from a significant weight loss due to their underlying illness. Regaining physical strength and nutritional status are essential to fully participate in your own self-care and cope emotionally with HEN. Keep in mind that reversing malnutrition is a gradual process; and you may not have a “textbook” response to treatment. Maintaining adequate hydration can also be challenging, especially if you have a diminished sense of thirst or increased fluid losses.

« ACT »
Consult your health-care provider if you are unable to maintain a healthy weight or experience gastrointestinal complications. Changes to your HEN regimen or medications may be needed. In addition, discuss how much water you require to meet your normal daily needs and to replace unusual losses during hot weather, exercise, diarrhea, etc.

Listen to your body

Learning to “listen to your body” can be helpful to conserve physical strength and adapt to HEN.

“If you don’t listen to your body, you kind of pay for it. You can kind of crash, and it’s harder to get back to some semblance of strength the next day.”

“If you’re strong-willed, which I think I was before, there comes a point where you do have to listen [to your body]. You can’t just ‘will’ yourself to do everything.”

“It probably took more than a year for me to figure out that you can read your own signals.”

« ACT »
Pay attention to your body’s early and subtle symptoms that tell you to relax, slow down or pace yourself. In addition, gastrointestinal complications (such as nausea, constipation or diarrhea) may signal the need for a change in your HEN regimen, medication or other medical treatment.

“I learned to handle the heat which was a problem because of the dehydration.”

“No one actually is textbook.”

“Eventually, you want your independence. Well, you can’t have the independence until you’re strong enough and you’re willing to give up something for that.”

One man described reversing the effects of severe weight loss and malnutrition: “You’re going to find that some things are going to come back faster than others, and it can take years for things to return entirely to normal. And that’s something I think if people are looking for anything to happen immediately, or within a short period of time, it doesn’t work that way. It takes a long time for the body to fully recover.”

“If you’re strong-willed, which I think I was before, there comes a point where you do have to listen [to your body]. You can’t just ‘will’ yourself to do everything.”

“It probably took more than a year for me to figure out that you can read your own signals.”
Strategy 10
Maximize your independence

Maximizing your independence and returning to activities you enjoy involves being prepared both physically and mentally. Taking charge of as many aspects of your own HEN regimen as possible is one way to increase your feeling of independence.

Enlist the help of family and friends
As you regain your independence, you may find that it is not always easy for caregivers to “let go” of their role as helper.

« ACT »
Talk openly with your caregiver. Discuss any tasks you could assist with or learn to do yourself and how you can work together to maximize your independence.

“In time, learn to feed yourself with the feeding tube. This will help you to return to a new sense of independence.”

“Then one day I just decided to change my dressing myself. It is just a matter of deciding to do it. Once you decide, that is 99% of the problem. Just say, ‘Hey I’m going to do that.’ It is just returning to the way you were.”

“I would say that learning is best accomplished by making mistakes. Helping a patient become independent is having the courage to let them make a mistake. So as a care provider, encourage independence.”

“Supportive family and friends have been good in terms of encouragement and understanding; sympathetic in a positive way, not an ‘oh poor you,’ but instead, ‘I know it is tough, but keep at it’ type of sympathy.”
Find what motivates you

The longing to resume enjoyable activities and “being tired of not being able to do what you used to do” can be strong motivating forces. Although physical limitations and HEN-related disruptions may prevent you from returning to many of your previous activities, think of ways to motivate yourself to engage in activities to whatever extent possible. Other HEN consumers are motivated because they want to:

• **Appear normal and feel accepted by others**

  “I want to appear as normal as I was before. I know I’m not, but I want to appear normal to other people.”

  “I think it is pride in yourself. You want to be able to be accepted by your peers, the public, or your friends. So to do that, you just resume where you left off, if you physically can.”

• **Resume enjoyable and rewarding activities**

  “Regaining a passion is an important part of recovery.”

  “The family was going to do their things anyway, they didn’t say ‘you have to come,’ they would say ‘when you are ready to come, fine’. But I didn’t want to be waiting at home for them. A driving force for me was that I wanted to participate. I still wanted to be with them.”

• **Reduce caregiver burden and resume responsibilities or obligations**

  “I liked working and wanted to get back to work and I also knew I had to do that. I had to worry about supporting the kids, the house; and working meant I could continue to fund my retirement plan. Those were important motivators to get back to as much normalcy as possible to do things with my family and some fun things, too.”

  “The motivation was to unburden my wife; the other was to demonstrate to me that I could be independent.”
Strategy 11
Minimize the disruption

Make your HEN regimen more flexible

Having the flexibility to make even minor adjustments to your HEN regimen can help to minimize the extent HEN disrupts your daily life. Although health-care providers may be unlikely to suggest any changes unless there is a medical reason, improving your quality of life is reason enough!

« ACT »

- Always consult your health-care provider before making any changes to your feeding regimen. The goal is to streamline the process to the extent possible without compromising safety, tolerance or nutritional status.

- Ask your health-care provider if there is any way to:
  1. Simplify your regimen (i.e., using ready-to-hang containers instead of cans; changing the enteral formula to minimize the need for supplements such as fiber, protein, or vitamins; using full can portions to avoid refrigerating open cans; or trying a slow gravity drip instead of an infusion pump).
  2. Make it more flexible to fit your lifestyle (i.e., varying the time, volume, or number of "feedings" while keeping your total daily nutrition constant).
  3. Reduce the infusion time (i.e., gradually increasing the rate as tolerated, or decreasing the number of feedings per day, while keeping the total volume the same; using a more concentrated formula; switching to a nighttime infusion).

Try an ambulatory pump

If you use an infusion pump, consider a lightweight version that has a long battery life and one that works in any position enabling you to move freely without stopping the flow of formula. These ambulatory pumps can help you resume a more active lifestyle, inspire a feeling of freedom, and enable you to overcome some of the social isolation that occurs when you feel "tied down."

"With the ambulatory pump on, I do things in my backyard — yard work and things like that, and even golf with the pump on."

"I still want to be able to sew; walk the dogs; the things I want to do. I'm 57 and I never thought I would be where I am at this point health wise. I want to live a quality of life the best I can. If it means taking the feeding pump in a backpack, then that's fine."
Strategy 12

Regain a healthy self-esteem

Feel good about yourself

The term self-esteem describes how people rate their self-worth, in part, based on how capable, valuable and/or lovable they perceive themselves to be. Many consumers suffer from a low or fragile self-esteem, especially when starting HEN. Feeling valued and supported by friends and confident in your ability to manage your HEN therapy are two ways to help rebuild your self-esteem and improve your ability to cope.

« ACT »
- Realize that you are no less valuable, capable or lovable because you require HEN.
- Re-connect with friends or join a support group (see Strategy 23 and Resources). Supportive relationships help rebuild your self-esteem by reinforcing that you are valued and loved.

Build self-esteem by helping others

Engaging in acts of good will and kindness can help build your self-esteem by providing an overall sense of satisfaction and accomplishment. Volunteering can provide an outlet for your skills and help compensate for the loss of career fulfillment. Volunteering in church groups, civic and support organizations and nursing homes, or participating in research studies are just some of the ways you might use your time, knowledge or skills to benefit others.

« ACT »
- Taking a genuine interest in another person’s needs can build empathy and take your mind off your own problems. Sometimes helping others just involves listening and allowing them to share their feelings with you.
- Strive to help someone else today. Give a small act of kindness by sharing your time, talents, abilities, money, good thoughts or prayers. If you need suggestions, ask a family member or trusted friend to identify ways your talents and skills can help others, or seek ways to mentor a new HEN consumer.

“I don’t feel any less of a person because I’ve got a tube coming out of me.”

“First, get support to know you are valued and loved for who you are and that you are not your feeding tube.”

“Seek a sense of accomplishment, having done something worthwhile, or having made a difference in some way. And if your disability doesn’t allow you to work full-time or part-time, then volunteering can provide a sense of accomplishment, doing something, making a contribution. It is great therapy.”

“You get strength from yourself. If you can do something successfully, or you do a good deed for yourself or for other people, that’s a strength.”
Strategy 13
Develop a positive body image

Physical changes resulting from HEN often make HEN consumers feel self-conscious or suffer from a poor body image. Negative feelings about your appearance, or feeling you are different from others, can also reduce your self-esteem. Your concerns about body image will likely diminish with time; these suggestions can help.

Be aware of unrealistic expectations
To some extent, we all judge others and ourselves based on physical appearance. It is a normal desire to want to look and feel attractive. Nonetheless, it is important to recognize that our society promotes unrealistic expectations of beauty.

« ACT »
- Accept that many changes in your physical appearance are outside of your control.
- Feel better about your appearance by emphasizing your best features and minimizing the appearance of the feeding tube or pump. Remember to smile — you will look and feel better.

Become aware of other people’s feelings
Coping with HEN involves being comfortable interacting with a wide variety of people from strangers to close friends. Being sensitive to other people’s feelings is important to foster healthy relationships. These suggestions may help you:

1. Don’t assume people even notice that you require HEN. It may be comforting to realize that other people are typically not very observant.
2. Seeing medical equipment can make some people uncomfortable. It is important to recognize that other people might be uncomfortable seeing your HEN equipment or a physical disfigurement. One strategy to help you cope with these situations is to show empathy for others, but also realize that you are not to blame if someone else feels ill at ease.

“You walk along with kind of a crazy feeling for the first six months, wondering, ‘what will people think of me with this tube in my stomach?’ And you get self-conscious.”

“Do not be embarrassed by the tube. You are alive and lots of people wear glasses. The tube is just another appliance to help us live a normal life.”

“Most of the public does not know you are tube fed. People on the street — don’t know, and they don’t care. Don’t feel inferior — because you are not, you just can’t swallow. The others can swallow.”

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“You walk along with kind of a crazy feeling for the first six months, wondering, ‘what will people think of me with this tube in my stomach?’ And you get self-conscious.”

“Do not be embarrassed by the tube. You are alive and lots of people wear glasses. The tube is just another appliance to help us live a normal life.”

“The others can swallow.”
3. Plant the seed of understanding. Although no one should be judged unfairly because of his/her appearance, some people discriminate partly out of ignorance. We are less likely to judge other people falsely when we understand their situation. If someone gives you a strange look, remember that he/she is probably just curious.

“On the whole, people may question me about my feeding tube, but it has never been anything negative — just curiosity.”

**« ACT »**

To the extent you feel comfortable, explain to others that your medical condition requires you to have a feeding tube. Write a brief statement explaining why you require HEN; and practice reading it several times until you are at ease stating it.

**Be kind to yourself**

As many thoughts are automatic or fleeting, you may be unaware of your inner dialogue (sometimes called *self-talk*). Engaging in negative *self-talk* about your appearance can worsen feelings of inadequacy and lower your self-esteem.

**« ACT »**

- The next time you look in the mirror, stop and become aware of what you think about yourself and how those thoughts make you feel. You may be your own worst critic. Instead of accepting your negative *self-talk* as the truth about your appearance, try to appreciate a positive aspect of your appearance or concentrate on what has not changed because of HEN.
- Learn to look beyond physical appearances (your own and others).
- When you see your HEN equipment, be grateful that it keeps you alive. Being thankful for what you have, rather than reminding yourself of what you lack, can help improve your overall outlook on life with HEN.
Strategy 14
Turn a problem into a challenge

To strengthen your motivation to try harder and ultimately succeed, try seeing the situation as a challenge to overcome, rather than a problem to endure.

« ACT »

Challenge yourself to improve. Start to view a problem as a challenge by turning it into a helpful competition with yourself or an opportunity for improvement.

“You make your own little challenges to yourself, one step at a time. You’re always challenging yourself about something.”

“One HEN consumer challenged himself to gradually attend more and more social gatherings where food was served. He started by joining the family at the table for short periods, and gradually increased the duration he would sit with them. With time, he progressed to joining family at fast-food restaurants where he wouldn’t be asked to order food. He eventually began to feel comfortable attending a wide variety of social gatherings.”

“Once I started HEN, the challenge was just trying to make it the best I could. Getting it down to a science where I could have it impact me as little as possible. Getting it down to a routine where I could do things quickly and not dwell on it.”

“You make your own little challenges to yourself, one step at a time. You’re always challenging yourself about something.”

“Beating the enteral feeding setback provides one more outlet for success.”

“I went through the process of saying, ‘Okay, how can I make this best for me?’”

“I made incremental, small, gradual steps. Meals at home with family, to meals with good friends who wanted to be encouraging, then meals with strangers, making that move over time.”

“One HEN consumer challenged himself to gradually attend more and more social gatherings where food was served. He started by joining the family at the table for short periods, and gradually increased the duration he would sit with them. With time, he progressed to joining family at fast-food restaurants where he wouldn’t be asked to order food. He eventually began to feel comfortable attending a wide variety of social gatherings.”
Coping successfully with HEN requires you to overcome many hurdles or at least change how you respond to them. Setting a goal is a strategy you can use to increase your likelihood of success. Goal setting enhances motivation, encourages you to identify the resources needed, and focuses your efforts. Choosing a measurable goal provides an objective target for improvement and enables you to monitor your progress and highlight improvements that might be barely noticeable on a day-to-day basis.

**Strategy 15**

Set and achieve your goals

Coping Well with Home Enteral Nutrition
Strategy 16
Develop perseverance

View mistakes as lessons
To solve HEN-related problems, you will probably need to rely on the trial-and-error method. Repeated unsuccessful attempts are frustrating; but do not underestimate the value of a mistake. Learning what did not work can be invaluable. You will cope more successfully if you can learn from your mistakes and modify your actions based on what you have learned.

« ACT »
Learn from your mistakes by viewing them as lessons in what not to do next time or how to react differently in the future. Think of another way to accomplish the task or imagine a more constructive response to your feelings of frustration or anger.

Try something new
Be open-minded and receptive to new ideas. This will help motivate you to keep trying alternative ways to overcome HEN-related problems.

« ACT »
- Be receptive. You may not want to hear advice from someone else. Nonetheless, if you remain open to suggestions, you will eventually be rewarded with a helpful idea.
- Let someone else’s idea inspire you to accomplish a task your own way. Modify or improve an idea to fit your unique situation.
- Try again later. What did not work in the past may be more successful now, especially if your attitude, body or the situation has changed.
- Use brainstorming to expand your options. Gather a supportive group and ask them to think of ways to solve a certain problem. To foster creative thoughts, instruct everyone to withhold any negative comments. Record each suggestion — no matter how crazy. Later, evaluate the entire list with an open mind.
- Necessity can be the mother of invention when you need to find a simple solution to every-day problems. Use creative problem-solving: instead of wishing someone else would invent a better product, use your imagination to design a practical solution, find innovative uses for common items, or devise a way to work around the problem.

A consumer who only received brief HEN instruction stated, “Pretty much everything else has been trial and error on my part.”

“Explore alternatives. Much of it is experimenting – what works for you.”
“There are multiple ways to get a good result. You have to be creative and try things out.”

“Habitual succeeders practice success.”

“Getting a small measure of positive reinforcement helps to give you the strength to counterbalance the huge negative pile of big problems and negative reinforcement.”

After a small personal success, one man recalled, “The acceptance of what I had to deal with came easier after that. Finding small things that allow you to congratulate yourself give you a greater ability to cope, become resilient, and overcome the larger problems. You don’t need to have a huge success, just a small one.”

When asked how she copes with being unable to eat, one HEN consumer stated, “You just tell yourself that you can’t, and you just have got to learn that. Sometimes your mind will let you do that, and sometimes it doesn’t.”

Success breeds success
Small successes in other areas of your life can increase your overall level of self-confidence and enhance your ability to cope with HEN-related problems.

Mind over matter works, but not every time
Strong-willed individuals can often make up their minds to do something and ignore their thoughts or physical sensations to the contrary. Nonetheless, a strong-willed temperament can be a mixed blessing when living with HEN forces you to accept the fact that some things cannot be overcome by determination or sheer will power.

A deodorant panty liner can help absorb drainage and minimize odor from around your feeding tube. Cut it in half and make a slit to fit on either side of the tube (absorbent side against the skin, do not pull off the backing). Tape it in place.

A good mortar and pestle is helpful to grind medicines to a fine powder. One consumer found an herb grinder in the kitchen section of a department store that worked better than one from the pharmacy.

« ACT »
Focus your efforts to change a situation — to the extent it can be improved. When the problem cannot be overcome, focus your efforts inward and use your strong will to shape how you can respond in a more constructive manner.
Strategy 17
Resolve negative emotions

Keep your emotions from escalating
You may experience many negative emotions resulting from the annoyances, daily hassles and serious challenges associated with HEN. Emotions such as fear, anger or frustration cause a hormonal reaction – the fight or flight response. Calming your physical body can also soothe your mind by allowing the hormonal response to subside.

« ACT »

Practice taking several slow deep breaths, getting some exercise, or trying another brief distraction.

Find constructive ways to express your emotions
Ignoring or suppressing unpleasant emotions does not make them go away. Taking time to grieve and expressing your emotions may help you clarify your thoughts and work toward resolving the underlying issue.

« ACT »

• Allow yourself time to grieve and express the sadness of your loss.
• If you are so inclined, put your thoughts in writing or discuss your feelings with a trusted friend or counselor.
• Some people find strength by trusting in a higher power to aid in resolving the situation, heal their emotions, or work toward forgiveness.

Get treatment for depression
Depression is a clinical illness that affects more than 19 million Americans each year (3,4). Although effective treatments are available, fewer than half of these individuals seek treatment (4). Many HEN consumers experience depression, which if untreated, impairs their ability to cope with the challenges associated with HEN.

Do not hesitate in contacting your health-care provider if you experience symptoms of depression such as prolonged or overwhelming sadness, hopelessness, loss of interest in activities you previously enjoyed, decreased energy, restlessness, difficulty thinking or concentrating, changes in weight, altered sleep habits, or thoughts of suicide.

Become aware of negative thought patterns
Your mind maintains a constant stream of thoughts, whether you are aware of them or not. We tend to believe these inner thoughts or “self-talk”. There-
fore, thoughts that focus on ways that you are not meeting your own expectations can contribute to feelings of low self-esteem and even depression.

« ACT »

Examining your thoughts and trying to put them into a rational perspective can be very beneficial. However, keep in mind that when you feel blue, your thoughts may not be accurate or realistic. Take a small notebook and keep it with you while you go about your usual day. Make note of any thoughts to yourself. Then, review your list of thoughts and see if you recognize any of the following limited-thinking patterns described by Dr. Aaron Beck (5):

Filtering – emphasizing negative details and ignoring positive aspects.

Polarized thinking – thinking something is either good or bad, perfect or a failure.

Overgeneralization – drawing a conclusion based on one example or event.

Mind reading – thinking you know how other people are feeling or why they are acting in a certain way.

Catastrophising – expecting the worst.

Magnifying – exaggerating the severity of a problem; feeling that even minor setbacks are overwhelming barriers.

Personalization – taking things personally, assuming that other people’s words and actions are related to you; or you comparing yourself unfavorably to others.

Shoulds – having expectations of how you and other people should act.

Identifying and correcting irrational thought patterns is a technique often used in cognitive psychology. If this technique interests you, contact a psychologist, psychiatrist or the American Psychiatric Association (see Resources).

Avoid factors that trigger your negative emotions

Determine if you can minimize the thoughts or situations that trigger unpleasant emotions. For example, if you become angry when viewing a television commercial about food, you might be able to think of several ways to avoid this stimulus such as changing the channel, muting the sound, or walking out of the room. Alternatively, challenge yourself to spend decreasing amounts of time experiencing anger.

Pat yourself on the back for the efforts you do make

Advances in healthcare have led us to expect instant relief for many ailments. Nonetheless, chronic therapies such as HEN require a continuous effort on the part of each consumer to adapt and successfully cope with new and ongoing challenges. It is unrealistic to expect yourself to “bounce back.” No one knows how hard you try to succeed more than you do. Be sure to give yourself credit for your hard work and effort — you deserve it.
Coping Well with Home Enteral Nutrition

Strategy 18
Accept what you cannot change

Many life changes will occur because you require HEN. For example, you may be forced to accept that you will require HEN indefinitely or adjust to physical limitations and the need to accept help from others. Therefore, it is important to have a realistic expectation about what you are able, or unable, to change.

« ACT »
Accepting your need for HEN can be an important aspect in your recovery, in part, because it helps you move forward. It is important to keep your hope alive but accept that you must try to make the most of your condition today.

Recite the serenity prayer
A spiritual source of strength may provide comfort by helping you accept undesirable life events and conditions you cannot change. If you are so inclined, the serenity prayer might be one source of comfort.

“God grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference.” — Reinhold Niebuhr

Find fulfillment in new activities
To help accept the fact that you are currently unable to participate in certain activities, find fulfillment by utilizing your talents in new ways or learning different hobbies and skills.

« ACT »
Seek alternative ways to use your skills and talents or learn a new hobby. Make a list of realistic things you would like to do or learn.

“If a feeding tube is inevitable, relax and accept it, don’t fight it. It isn’t that bad.”

“It takes a while for someone who thought they could control everything to accept the treatment. Then all of the sudden it is the acceptance. And admitting you can’t handle everything on your own.”

“If you accept that you must have HEN, you look for reasons to feel fortunate. I know what the alternative would be — I wouldn’t be here. How can you look at that alternative and not feel grateful to be experiencing things that you otherwise couldn’t?”

“You accept it [HEN] only because you have no choice. I understand that I have to be tube fed, and do I accept it — I accept it like you brush your teeth every day. I think the word is more of a resignation. You have to keep accepting it. And as time goes on, I just took a hold of myself, and said, ‘This is the way it is, and this is the way it’s going to be.’”

“If a feeding tube is inevitable, relax and accept it, don’t fight it. It isn’t that bad.”

“It takes a while for someone who thought they could control everything to accept the treatment. Then all of the sudden it is the acceptance. And admitting you can’t handle everything on your own.”

“If you accept that you must have HEN, you look for reasons to feel fortunate. I know what the alternative would be — I wouldn’t be here. How can you look at that alternative and not feel grateful to be experiencing things that you otherwise couldn’t?”

“I know I’m more limited, because I can’t do certain vigorous things like I did before. But I’ve come to peace with that, and I certainly do enough things to keep me happy and the most important thing for me is that I see my family growing up and doing things.”
Strategy 19
Expand your coping strategies

Most people repeatedly use the same coping strategies, even if they are ineffective. A key factor in learning to cope more successfully with HEN is the ability to use a wide variety of coping strategies. In addition to resolving HEN-related problems by changing the situation, it is critical to learn how to alter your response to the problem, or do a little of both.

Change the situation

Earlier in this manual, several coping strategies were suggested that can minimize the stress of HEN by resolving a problem or changing the situation (such as finding information about new products and equipment, or learning more efficient ways to master HEN-related tasks). These strategies work best when you have some control over the situation.

Improve your response

Living with HEN also requires you to deal with the stress of many problems that are irreversible or cannot be improved despite your best effort. In these situations, efforts to cope must focus on changing the way you think or feel about the situation (such as can occur when you discuss your feelings with a counselor or uncover deeper insights by writing in a journal). Changing the way you think or feel about a situation is called emotion-focused coping. These strategies can help minimize the stress of unresolved problems, or provide temporary relief from situations outside of your control. Practice using these strategies frequently, and in the most constructive manner.

« ACT »

Increase your arsenal of coping strategies by using one or more of the following methods:

- Change how you view the situation. View the situation more objectively or try to imagine an alternative explanation. Alternatively, change your point of view by trying to look at the problem from another person’s perspective.
- Distract yourself. To break the cycle of dwelling on negative emotions, or to prevent disturbing thoughts from escalating, divert your attention. Engage in activities that are enjoyable or enhance meaning and purpose in your life. For example, you might listen to uplifting music; read a book; sew; watch a movie; visit or call a friend; or go for a walk.
• Turn negative emotions into constructive actions. Feelings of frustration, anger, or blame can be the spark that motivates you to work harder and take constructive actions to resolve the problem.

• Search for benefits. Learn to appreciate aspects of your life that are enhanced because of HEN (see Strategy 27).

• Seek meaning or purpose in the experience. You may find it uplifting to search for meaning and purpose in your experience of living with HEN. Sharing your knowledge with other HEN consumers is one way to experience the benefit of helping others who share a similar experience. If you are so inclined, use spiritual techniques such as prayer, meditation, attending a religious service, or reading scriptures.

• Compare yourself favorably. We all compare ourselves with others. Unfortunately, when you compare yourself to someone you think is superior in some way (physically, mentally, financially, socially, etc.) it is likely to make you feel inferior. Instead, compare yourself to someone in a similar or worse condition. In this manner, you are more likely to view your own situation in a more positive light.

Comparing yourself to other people can also inspire you. Seeing other consumers who are coping successfully with HEN is motivating and inspirational.

“Well, if she can do this, why can’t I?”
Strategy 20
Seek and accept support

Having supportive relationships, where you feel valued and cared about by others, is a basic human need. Supportive family members and friends can help you overcome feelings of social isolation, provide emotional support, find useful resources, promote your independence, and assist with problem solving. Be willing to ask for help, and accept it when it is offered; because these are critical strategies to enhance your ability to cope with HEN.

Recognize and accept the need for support

It can be difficult to accept that you can no longer do everything for yourself, especially if you were previously very independent.

« ACT »
Evaluate your current situation to recognize the types of assistance you require (physical or emotional support, financial or educational resources, new or adaptive equipment, etc.), even if the need is only temporary. Talking with your caregiver, health-care provider, or trusted friend can help to identify your needs more objectively, which is the first step in getting the assistance you require.

Be willing to ask for help

You may be hesitant to ask for help because you do not want to be a burden; or you might worry that asking for help is a sign of weakness. Typically, these fears are unfounded or exaggerated because friends and family genuinely want to help. Nevertheless, the desire to relieve the burden of caregivers can be a strong motivating factor in your effort to regain independence.

« ACT »
An open and honest discussion can clarify your needs and identify the extent to which others can help. Remember to be objective and realistic; and that the needs of both parties will change over time. Therefore, it is critical to keep the lines of communication open.

“Even the strongest, most independent people realize that support is very helpful.”

“A support system is totally necessary and I just can’t emphasize that enough.”

“It’s all about connections.”

“As appropriate, don’t be afraid or embarrassed to ‘hand over’ responsibilities of your life to others. A good supportive family is an absolute blessing and an effective motivator.”
“It's not your fault you're limited — ask for help when needed.”

“People that you want around just understand the situation and make nothing of it.”

**Be specific**

You cannot expect someone else to read your mind or anticipate your needs. Although your needs may seem obvious to you, your loved ones will not always know how or when to help. Be sure your requests are specific and polite.

**« ACT »**

When someone offers to help, suggest one or more specific tasks that you would like him/her to do. Try to tailor your request to the person’s interests or skills whenever possible. Alternatively, write a “helping-hand wish list” outlining several chores that need to be done or that you could use help doing. Then, let the person choose what appeals to his/her abilities and time.
Strategy 21
Build a broad network

You may wonder, “Where can I turn for help”? With a little creativity, effort, and an awareness of resources, you can increase your available support.

« ACT »

- Think “outside the box” to find at least one new avenue of support. Look in the newspaper for local support groups, contact an old friend, resume attendance at a social or religious organization, meet someone new by starting a hobby, ask a social worker or discharge planner to help, contact the Oley Foundation, or discover your own inner source of support.

- If you have access to a computer, online support groups are available for HEN consumers. They may offer useful suggestions although the accuracy of the information cannot always be guaranteed. In addition, remember that people are more likely to write about their negative experiences. Try to avoid feeling overwhelmed by other people’s problems or fearing unlikely complications, especially when reading about people whose condition is different from your own.

- Some support organizations have letter or e-mail pal programs set up that allow you to communicate with others going through similar circumstances (i.e., the Oley Foundation and the Crohn’s and Colitis Foundation – see Resources).
Strategy 22
Nurture those who help and support you

When your personal needs are overwhelming, it is easy to overlook the fact that the people assisting you also need to be nurtured. Simple actions on your part can help rejuvenate caregivers and others who support you.

« ACT »
- Voice your gratitude often and sincerely.
- Remember the basics like saying “please” and “thank you”. Do not forget your manners just because they are family or close friends.
- Do as much for yourself as possible. People are naturally more inclined to help others who sincerely want to help themselves.
- Help prevent caregiver burnout. To reduce caregiver fatigue, find respite care that provides time off early and frequently. (See resources)
- Recognize the needs of your family and friends. Becoming sensitive to the physical and emotional needs of others establishes a mutually supportive relationship.
- Show empathy. Your need for HEN has likely affected the lives of those around you.
- It is natural to want to give back to those who help you. Ways to demonstrate your appreciation include resuming social activities your partner enjoyed, joining him/her at a restaurant, praying for others, or cooking someone’s favorite foods.

Be aware of what you say and how you say it
The way you communicate influences how people respond to you.
- Be aware of your tone of voice and facial expressions. Body language can speak louder than words to convey your true feelings.
- Avoid personal criticism that can lead to defensiveness. Use objective statements that describe how you feel instead of implying the other person is at fault.

« ACT »
Practice using “I” statements instead of “you” statements. For example, state “I feel angry when you…” instead of “You make me angry when you….”
Strategy 23
Join a support group

Support groups encourage discussion and exchanging of resources among people who share a similar experience. The opportunity to communicate your feelings openly can aid in coping, especially when you feel accepted by others and are given a chance to grieve. Yet, you may not want this type of interaction or prefer to gain information more privately. Therefore, numerous support organizations offer a variety of educational resources and outreach services. Participating in a support group can offer many benefits such as:

- Tips to prevent or treat common complications and minimize unwanted side effects
- Awareness of innovative equipment and the latest treatment options
- Practical advice from people who have overcome similar challenges
- Medical information written by experienced health-care providers
- Comfort from knowing that you are not alone in your experience
- Inspiration from role models and mentors
- The option to share their knowledge and/or communicate with other consumers
- Useful resources to simplify your search for information

« ACT »

Join a support group (see Resources). The Oley Foundation is a valuable resource for education and outreach because it specializes in the needs of home enteral (and parenteral) nutrition consumers and their caregivers.

“Identifying with someone who has faced the same challenges [enhances coping].”

“You can do a lot yourself, but everyone needs support. I don’t think I realized that until I went to an Oley Foundation conference and saw examples of people who had dealt with worse situations than mine and had managed HEN so well that I knew I could, too.”
Strategy 24
Be aware: relationships will change

Some relationships get better while others may not

To varying degrees, your relationships with family and friends will likely change because of living with HEN. Sharing a major life event can strengthen and deepen some relationships and you may experience enhanced feelings of appreciation and support from your loved ones. However, other relationships may be unable to withstand the stress and life disruptions frequently associated with HEN. For example, you may be unable to resume previous social activities and thus endure periods of feeling withdrawn and socially isolated.

« ACT »
• Try not to feel personally responsible if a friendship is unable to withstand changes brought about by HEN. Look for positive ways to view the situation and work to surround yourself with friends who support and accept you.
• By definition, support involves both give and take. Reach out; even if you feel someone else should be contacting you, go ahead and make the effort.
• No matter how much they love you, people become weary of hearing about your medical problems. Stop focusing on your own problems and make a conscious effort to balance the conversation with other topics and be attentive to what is going on in other people’s lives.

Roles will evolve

Your life is comprised of many roles. For example, you may currently be a sibling, parent, spouse, friend, employee, etc. Although roles constantly evolve, established relationships are familiar and it is difficult to accept when roles suddenly change because of a major life event, such as becoming HEN-dependent. You may experience a void if you are no longer able to participate in roles that helped form your personal identity, or feel inadequate if you are unable to fulfill responsibilities to the extent you desire. It is important to find other ways to feel needed and contribute to these relationships.

« ACT »
Think of a relationship where you would like to be more involved. Imagine how you could expand or change your role to include new ways to share your love and talents in that relationship.
Strategy 25
Find comfort in faith

During times of illness and strife, people often turn to a spirituality or reaffirm their affiliation with a religious group. For some people, a spiritual source of strength may enhance coping by:

- Fostering a sense of peace
- Being an avenue for forgiveness
- Building hope and emotional strength to endure burdens
- Offering a sense of meaning
- Bringing comfort by releasing problems to a higher power
- Receiving support from others attending the same place of worship

« ACT »
If you are so inclined, your need for HEN can provide an opportunity to renew your faith and seek comfort through a spiritual source of strength.

“Spend time in prayer each day.”

Resolve inner conflict

Enduring a serious illness or chronic therapy may cause some HEN consumers to question their faith; furthermore, the religious convictions of loved ones may result in conflict. It is important to seek resolution to inner conflict because some research has found that individuals who experience prolonged spiritual struggles had worse medical outcomes compared to those who did not experience an inner spiritual conflict (6).

« ACT »
If you are so inclined, discuss your concerns with a spiritual leader, trusted family member, or counselor. Alternatively, books are available on the topic that might be helpful such as When Bad Things Happen to Good People by Harold S. Kushner.
Strategy 26
Seek enjoyment at meal times

“If you avoid meals you are going to miss a lot of other things. Why let your emotions get in the way?”

“Taste is 90% smell. Your mind does accept that you are having your meal.”

“Make dinner exciting. Each evening design an imaginary menu of what you would like.”

“To help overcome food craving — a lot of it is psychological. I can juice some of the foods I loved, and it’s psychological. It’s just telling me that, “Yes, you are eating a favorite food, but you can’t taste it.” But it’s there; it’s in your system.”

Focus on other reasons to be together

Although food is a major focus at essentially all social gatherings, there are typically more important reasons to attend. Reflect on the importance of the gathering — such as enjoying the company of family and friends, celebrating religious and cultural traditions, or conducting business transactions.

Dealing with the loss of food

HEN consumers have offered suggestions to help compensate for the inability to eat. As each person’s medical condition is unique, always talk with your health-care provider before making any change in your oral diet or enteral formula.

- **Use your other senses** — and a great deal of imagination
  Pretend that you are eating. Breathe in the aroma. If medically safe to do so, chew gum or suck on a hard candy with a strong flavor.

- **If tolerated, supplement your formula with a little regular food**
  Some consumers are able to tolerate infusing certain foods through their feeding tube that have been blended and strained or put through a juicer before putting the liquid through their feeding tube.

**Caution:**
The use of blenderized/strained or juiced foods to supplement a commercially prepared enteral formula can reduce cost, may provide some additional nutrients such as antioxidants and phytochemicals, and for some, have a psychological benefit. Nonetheless, health-care providers do not routinely recommend this practice because of the time and inconvenience, risk of bacterial contamination and tube occlusion, and variability of nutrient content. Always be sure to discuss the potential risks of this practice with a Registered Dietitian or another experienced health-care provider. For example, many foods and beverages can result in gastrointestinal complications especially if the intestinal tract is compromised due to disease, or if the food is infused directly into the small intestine. Furthermore, food that is too hot or too cold when infused through the tube may cause discomfort.
• You can still benefit from cooking

Enjoy the creative process of cooking and the opportunity to nurture loved ones.

Be a good companion

Although you may feel ill at ease joining people who are eating, it is important to realize that your companions may also feel guilty eating in front of you. Show compassion and understanding for your dining companion(s):

• You can make others more comfortable by lightening the mood with humor or making the situation seem like it is “no big deal” to you.

• Some people are hesitant to dine alone at a restaurant or neglect eating if not encouraged. Be a good companion — join them at the table for their benefit.

• Family members may be reluctant to attend social events without you. Accompany them — and feel good knowing they are not limiting social activities because of you.

• Make the meal or event more fun by sharing your talents. Join in the fun by playing the piano as background music or being the waiter.

Restaurant Cards are available free of charge from the Oley Foundation that can help HEN consumers explain to wait staff why they are not ordering food or drink.
Strategy 27
Focus on the positive

Learn to be more optimistic
Having a positive attitude can help you cope with many of life’s challenges, including HEN. Some people seem to be born with a more optimistic outlook than others. Nonetheless, a noted behavioral scientist, Dr. Martin Seligman, believes traits such as optimism are only partially explained by genetics, and thus can be influenced by factors such as your thoughts and environment.

« ACT »
Whether you describe yourself as a naturally optimistic or pessimistic person, you may learn to be more optimistic and diminish the tendency to view a situation in a pessimistic way. To learn more about this technique, read one of Dr. Seligman’s books such as Learned Optimism: How to Change Your Mind and Your Life, or Authentic Happiness.

Foster an attitude of gratitude
Taking time to be thankful for your blessings can help you become more aware of the good aspects of your life that could easily be taken for granted.

« ACT »
- Practice thinking and saying words of appreciation. Each day, write down at least three things for which you are grateful. When you feel overwhelmed by negative life events – review the list.
- Although you might describe HEN as a necessary evil, you can still work to minimize the negative and maximize the positive aspects of HEN. Begin to change your perspective by searching for the hidden benefits of HEN.
Describe yourself coping with HEN

The consumers who contributed information for this manual offered their definition of coping successfully and being resilient with respect to life with HEN. Here are two examples:

“A resilient person with respect to enteral feeding is one who:

(a) recognizes that the enteral feeding is a blessing (some doctor or researcher in the past figured out how to feed people who otherwise might die of malnutrition);

(b) weighs the amount of life lived as opposed to the amount of time lost in enteral feeding (if you spend 1 hour a day or 6, you still have 23 or 18 hours left to live; that’s pretty good odds); and

(c) reasons with one’s close acquaintances that it’s an honor to be in their presence (the alternative is death and that would not be an option they’d prefer).”

“Think of a rubber band. If you put a weight on it, it is going to stretch out. Think of the weight as your disability. The rubber band is stretched down to the bottom because of this heavy weight, this disability. Being down there at the bottom is coping, but resilience is coming back up again. That’s resilience, coming back to normality. It’s more than just coping.”

« ACT »

Write your own description of someone who is coping successfully with HEN. Then plan ways you can work toward fulfilling it.

Rediscover life’s simple pleasures

Experiencing a severe health challenge and the need for HEN are life-altering events, which can have the unforeseen benefit of changing your perspective on what is most valuable in your life.

« ACT »

Make a list of what is important in your life (relationships, accomplishments, a special talent, career, goals, social activities, spirituality, responsibilities, etc.). Think about the extent to which you would like to increase (or decrease) your involvement in each of those relationships and activities, and focus your energy on the things that are the most worthwhile.
Strategy 28
Laugh more and relax

Your thoughts and emotions can have a profound influence on your physical and mental health. For many people, laughter is truly a powerful form of medicine. Relaxation techniques can also be highly effective — if you take the time to practice them regularly.

Make light of the situation

« ACT »

• Make light of the situation. For example, if you or your companion is uncomfortable at a meal, using humor to lighten your mood (or the frame of mind of others) can help everyone relax and enjoy the experience.

• Read comics and jokes. See light-hearted movies — whatever makes you laugh. You’ll feel better.

• Write about your experiences in a humorous light.

Relax

Whether you feel stressed by major life events or daily hassles associated with HEN, remaining calm can help you think more clearly and rationally. Setting aside time each day to practice some form of relaxation therapy can improve your overall ability to cope. Be open-minded and try several relaxation techniques to find the one you enjoy and can fit into your daily routine. Examples include yoga, meditation, and tai chi. Learning techniques to be more engaged in the present moment (rather than regretting the past or worrying about the future) can also be helpful. Furthermore, music can be a creative and therapeutic outlet and music therapy has been shown to soothe individuals in a variety of medical situations.

« ACT »

• Get into a routine of practicing some form of relaxation therapy every day.

• If you are saying to yourself, “I have no time to relax,” remember that most people find taking even short periods of time to unwind will make their day more efficient by clearing their mind and helping them feel less rushed.

“The biggest thing is to learn to laugh about it. Learn to make jokes about it. Don’t take it too seriously.”
Strategy 29
Search for resources

This list is intended to guide your search for HEN-related information and services and is not an exhaustive list of resources.

Identify reliable online information

The old adage, “You can’t believe everything you read” — certainly applies to information on the Internet. Information that is inaccurate, incomplete, or biased to sell a product can be misleading and put you at risk of making inappropriate healthcare decisions. As the number of Web sites can be overwhelming, even to savvy consumers, seek assistance from a medical librarian, or ask your health-care provider to suggest reliable Web sites.

« ACT »

Search only those sites providing up-to-date and reliable health information. Use the following questions to narrow your search:

1. How reliable is the Web site?
   - The source should be evident (such as the National Institutes of Health - http://www.nih.gov). Sites sponsored by the government include “.gov” in the Web address; “.edu” indicates an educational institution; “.org” Web sites are used by professional and non-profit organizations; and “.com” indicates the site has a commercial nature and any information should be judged accordingly.
   - Some Web sites review the reliability of online resources (such as Tufts University Child & Family Web Guide http://www.cfw.tufts.edu/) or evaluate health information published in newspapers and magazines (Health News and Review - http://www.HealthNewsReview.org).

2. Where did the facts originate?
   - Valid medical claims are backed by rigorous research studies published in reputable medical journals. Testimonials and opinion are not scientific evidence.
   - The author of the material and sources of information used must be clearly stated.

3. Is the information up-to-date?
   Medical facts need to be evaluated for accuracy and updated. The publication date, or the last time the information was reviewed for accuracy, should be posted.

4. Does it sound too good to be true?
   Remain skeptical and seek agreement from other sources.
Join consumer education and support groups

Home parenteral and enteral (HPEN) nutrition consumers and families

1. The Oley Foundation
   214 Hun Memorial, MC-28, Albany Medical Center
   Albany, NY 12208-3478
   1-800-776-OLEY; 1-518-262-5079
   http://www.oley.org or e-mail: bishopj@email.amc.edu

   Offers up-to-date medical information related to HPEN therapies and opportunities to meet others on home tube and intravenous feedings. Printed materials such as an HEN Complication Chart and Travel and Hospitalization Packet are available online or by calling toll-free.

2. Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT)
   http://www.pinnt.co.uk/

   Materials on this site are intended primarily for the use of persons accessing it from within the United Kingdom.

Disease-specific organizations

1. National Stroke Association
   9707 East Easter Lane
   Centennial, CO 80112-3747
   1-303-649-9299, 1-800-STROKES (1-800-787-6537)
   http://www.stroke.org

2. American Stroke Association
   7272 Greenville Avenue
   Dallas, TX 75231
   1-888-478-7653
   http://www.strokeassociation.org

3. National Cancer Institute, NCI Public Inquiries Office
   6116 Executive Boulevard, Room 3036A
   Bethesda, MD 20892-8322
   1-800-4-CANCER; 1-800-422-6237
   http://www.cancer.gov/

4. Crohn’s & Colitis Foundation of America
   386 Park Avenue South
   17th Floor
   New York, NY 10016
   http://www.ccfa.org
Seek information from reliable sources

Consumer health information
   Medline Plus: http://medlineplus.gov/
   (Search health topics such as nutrition, nutrition support, drugs & supplements)
   Health Information: http://health.nih.gov
2. WebMD
   http://www.webmd.com/
3. Emedicine Consumer Health
   http://www.emedicinehealth.com/
   Center for Disease Control and Prevention: http://www.cdc.gov
5. American Academy of Family Physicians (AAFP)
   http://familydoctor.org/
6. MayoClinic.com, Mayo Foundation for Medical Education and Research
   http://www.mayoclinic.com/
7. NOAH: New York Online Access to Health
   http://www.noah-health.org/
8. Food and Nutrition Information Center
   http://www.nal.usda.gov/fnic/
9. University of Virginia Health System, Digestive Health Center of Excellence
   http://www.healthsystem.virginia.edu/internet/digestive-health/nutrition/resources.cfm

Medical research
   (Search medical literature)
2. Highwire Press, Standford University Press
   http://highwire.stanford.edu/
   (Obtain free copies of full-text medical literature)

Healthcare quality and research
1. Information on Clinical Trials and Human Research Studies
   http://clinicaltrials.gov/ct/gui
2. Agency for Healthcare Research and Quality
   http://www.ahrq.gov/consumer/

Complementary and alternative therapies
National Center for Complementary and Alternative Medicine
http://nccam.nih.gov
Find a specialist
Finding health-care providers experienced in the needs of HEN consumers can be challenging. Request a professional who is knowledgeable about the risks and benefits of HEN products, and who keeps up-to-date on reliable sources of information.

Wound care resources
Wound, Ostomy & Continence Society
http://www.wocn.org/
(To find a WOC Nurse referral, click on “Patient Referral” and choose “Search for a WOCN member in your area”)

Registered Dietitians
American Dietetic Association
120 South Riverside Plaza, Suite 2000
Chicago, Illinois 60606-6995
Phone: 1-800-877-1600
www.eatright.org
(Click on “find a nutrition professional” on the homepage.)

Nutrition Support Dietitians, Nurses, Pharmacists, and Physicians
American Society for Parenteral and Enteral Nutrition
8630 Fenton Street, Suite 412
Silver Spring, MD 20910
1-301-587-6315
http://www.nutritioncare.org

Pharmacists
Board of Pharmaceutical Specialties
http://www.bpsweb.org/
[Click on the “locate specialists” tab, then search by specialty (nutrition support pharmacy) and location (state).]

Physical Therapists
American Physical Therapy Association
1111 North Fairfax Street
Alexandria, VA 22314-1488
1-703/684-APTA (2782) or 1-800/999-APTA (2782)
http://www.apta.org
(On the homepage, click on “Information for Consumers” then “Find a PT.”)

Occupational Therapists
The American Occupational Therapy Association, Inc.
4720 Montgomery Lane
PO Box 31220
Bethesda, MD 20824-1220
1-301-652-2682
http://www.aota.org/
(Click on the “consumer” link on the homepage.)
Speech Therapists
American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852
1-800-638-8255
http://www.asha.org/
(Click on “The Public” link on the homepage.)

Mental health resources
1. American Psychiatric Association
APA Answer Center
1000 Wilson Boulevard, Suite 1825
Arlington, VA 22209
1-888-35-PSYCH, 1-703-907-7300
http://www.psych.org
(Click on “Mental Health Resources” and other interesting links from their homepage.)
or e-mail: apa@psych.org

2. National Institutes of Mental Health
1-800-421-4211
http://www.nimh.nih.gov
(To help you search for resources, click on the “Mental Health Topics” under the “Health and Outreach” category.)

Find products and therapies of interest
1. Swallowing therapy
VitalStim® Therapy
1- 800- 506-1130
http://www.vitalstim.com

2. Nestle Nutrition
Enhancing the Quality of Life – Dysphagia Online
http://www.dysphagiaonline.com

3. Logan’s G-tube Accessories
3317 S Raintree Dr
Nampa, ID 83686
1-208- 697-1196
http://www.TummyTunnels.com
or e-mail: TummyTunnels@yahoo.com

4. Applied Medical Technology, Inc.
8000 Katherine Boulevard
Brecksville, OH 44141
1-440-717-4000, 1-800-869-7382
info@appliedmedical.net
http://www.appliedmedical.net
Respite care resources
1. ElderCare Locator
   1-800-677-1116
   http://www.eldercare.gov

2. The Family Caregiver Alliance
   1-800-445-8106
   http://www.caregiver.org

3. Contact your state or local agencies on aging. Ask about caregiver support programs that include respite care.

4. Local chapters of some disease-specific groups such as Alzheimer’s Association
   1-800-272-3900
   http://www.alz.org/findchapter.asp

5. The National Institute on Aging includes a list of caregiver resources
   http://www.nia.nih.gov/
   (Click on "Publications")

Enteral formula, supplies, infusion pumps, and other products
1. Abbott Nutrition, Abbott Laboratories
   Abbott Nutrition Consumer Relations
   625 Cleveland Avenue
   Columbus, Ohio 43215-1724
   1-800-986-8510
   http://abbottnutrition.com/

2. Nestle Healthcare Nutrition
   800 N. Brand Boulevard, 9th Floor
   Glendale, CA 91203
   1-800-422-ASK2 (2752) OR 1-800-333-3785
   http://www.nestle-nutrition.com/

3. Covidien (formerly Tyco Healthcare/Kendall)
   15 Hampshire Street
   Mansfield, MA 02048
   1-800-962-9888
   http://www.kendallhealthcare.com

4. Zevex International
   4314 ZEVEX Park Lane
   Salt Lake City, Utah 84123
   1-801-264-1001, 1-800-970-2337
   http://www.zevex.com/

   5425 W. Amelia Earhart Drive
   Salt Lake City, UT 84116
   1-801-595-0700, 1-800-545-0890
   http://www.bardaccess.com
Choosing a health-care provider or hospital

1. The National Institute on Aging
   1-800-222-2225
   http://www.nia.nih.gov/
   (Click on “Publications”)
   Information is available on a variety of health topics including
   Choosing a Doctor, Talking with Your Doctor, and Online Health Information — Can You Trust It? Many are free and available in both English and Spanish.

2. Hospital Compare – from the U.S. Department of Health and Human Services
   http://www.hospitalcompare.hhs.gov/
   This Web site allows you to review how specific hospitals rate on the care they provide to patients with certain medical conditions. In addition, a “hospital checklist” offers questions patients should ask prior to admission.

Financial issues and reimbursement

Health-care providers understand that the cost of medical care can be unexpected and place a huge financial burden on consumers. Tell your health-care provider if the ability to pay for a treatment or medication is a concern. He/she may be able to guide you to other resources, or identify more cost-effective options.

1. Centers for Medicare and Medicaid Services
   http://www.cms.hhs.gov

2. Medicare
   http://www.medicare.gov

3. Abbott Nutrition Reimbursement Help Line
   1-800-558-7677

4. Nestle Nutrition Reimbursement
Conclusion

This manual highlighted how HEN consumers took personal responsibility to cope more successfully with their therapy. Each of these consumers used a variety of coping strategies and relied on using their unique strengths to find what worked best for them. Although one strategy or technique will not work for everyone, try the strategies that you and your health-care provider feel are best for you.

References


Evaluation Form

Please take a few moments to complete the following evaluation form. Your comments and suggestions are needed to assure that this educational resource offers useful information and a message of hope to HEN consumers.

1. I am a ________ clinician, ________ consumer, ________ other.

2. Overall, how useful is this manual to foster coping?

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3. Was the language too technical or difficult to read? ________ yes, ________ no

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4. Which strategies did you find most useful? ____________________________________________
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5. Which strategies did you think were least helpful? ____________________________________________
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6. List any additional resources you have found useful that might be included in a revised manual. ________
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7. If you are a clinician:

Would you print this manual to give to HEN consumers for whom you provide care?
_______ yes, ________ no, ________ only for some consumers

Comments: ____________________________________________
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Please return the completed form to:

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