What to Eat? What to Drink?

by Carol Ireton-Jones

What’s for dinner? It is the age-old question of moms, dads and families everywhere. However, when you have gastrointestinal (GI) challenges, the question isn’t so much “What’s for dinner?” as it is “What can I eat?” There are unique dietary tolerance differences for everyone with GI challenges. What you can eat depends on your GI anatomy, including how much small bowel and colon you have remaining, which part is remaining, and whether or not it works properly. Most people with GI disease who receive full or partial home parenteral nutrition (HPN) learn about what foods they can tolerate from their dietitian, nutrition support clinician or physician. In some instances, they learn through trial and error. If you have GI challenges, the following suggestions may be helpful to you.*

♦ Fruits
  • Skinned fruit; most canned fruit is fine
  • Fruit juices diluted with water or sugar-free soda without sorbitol
  • Fruits that are not always tolerated include pineapple and pineapple juice, and orange juice (even those juices with low acidity and without pulp)

♦ Vegetables
  • Skinless vegetables that are cooked until soft
  • Steamed squash, such as yellow zucchini
  • Tomatoes, mushrooms and green beans that have been cooked well
  • Vegetables that are not always tolerated include raw or cooked carrots, corn, black olives, and raw or cooked spinach

♦ Breads and cereals
  • Low fiber breads and cereals
  • Ground whole wheat rather than whole grain
  • Flour tortillas, not whole wheat or corn
  • Breads and cereals with the highest nutrition rating

♦ Dairy
  • Low to moderate intake to avoid lactose intolerance
  • Harder cheeses that contain less lactose
  • Skim or 1-percent milk
  • Yogurt, only if it has been approved by your physician

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I have been diagnosed with gastroparesis. I have lost five lbs. over the past two months and have bouts of nausea and vomiting. What are my options?

Patients with gastroparesis, or problems with food and fluid emptying from their stomach into their small intestine, often will have frequent nausea and vomiting resulting in an overall reduction in food and fluid intake. Weight loss and dehydration may develop. Dietary modification can be helpful. Fats in the diet delay gastric emptying, so the use of a low fat diet may prove useful. Patients also will tolerate frequent small meals better than fewer large meals. There are some medications that improve gastric muscle contractions resulting in food and fluid moving into the small bowel more efficiently. These medications are known as “promotility agents” and include metoclopramide, erythromycin and domperidone.

Another option is the implantation of electrodes in the stomach that are connected to a generator on the abdominal wall (gastric pacemaker). The electrodes deliver a stimulus to the gastric wall muscle to encourage muscle contractions. Some centers have reported good results with this device. Finally, a feeding tube, known as a jejunal tube or J-tube, may be necessary. This tube enables patients with gastroparesis to receive food, fluids or medications. In addition, some patients may require a separate gastric feeding tube, such as a percutaneous endoscopic gastrostomy (PEG), that is used to drain fluids and food from the stomach whenever a patient develops nausea or vomiting.

I have short bowel syndrome as a result of multiple small and large bowel resections for Crohn’s disease. I have been on parenteral nutrition for two years and have had one catheter infection. However, summer is arriving and I always seem to get dehydrated on my normal parenteral nutrition prescription. Why is this happening?

Patients who are on long-term parenteral nutrition often do not absorb much, if any, fluids from the small intestine or colon. Therefore, they are totally dependent on their parenteral nutrition prescription to deliver not only protein, calories, vitamins and minerals, but also fluids. There are formulas available which allow your doctor, pharmacist or nurse to calculate your average daily fluid needs. Certain situations may require a lot more fluid than would be anticipated from someone’s daily fluid needs. We see this in patients with frequent nausea and vomiting, high ostomy fluid outputs, severe diarrhea or excessive urination. We also see this in the summertime when excessive sweating or fluid loss needed for mucous membranes, such as the mouth, dramatically increases fluid needs.

In order to address the need for more fluid in patients during the summer months in the USA, various treatment options are available. One option is to increase the total amount of fluid in a patient’s parenteral nutrition prescription each day during the summer months. The parenteral nutrition prescription can be decreased in total fluid volume during the other seasons of the year. Alternatively, patients can keep one to two liters of normal saline (an intravenous fluid) in the refrigerator and infuse one liter at a time when they start to feel dehydrated. In addition, patients will lose sodium and chloride in their sweat. Sometimes, it will be necessary to increase the sodium and chloride content of the parenteral nutrition prescription. The use of supplemental intravenous saline will help to replace both sodium and chloride.

If you have any questions that you would like answered in Dr. DeLegge’s “Ask the Nutrition Doctor” column, you may send those to celebratelife@coramhc.com. We look forward to hearing from you.
Oral Rehydration Solutions

The status of your GI tract — its length, its motility, and the presence of disease — may affect your GI output. In some instances, you may be able to decrease some of the fluid in your intestine and increase absorption by increasing your fiber intake. On the other hand, too much fiber can cause uncomfortable side effects; therefore it is recommended that you consult with your doctor or dietitian prior to making changes in your diet. Your doctor may also prescribe anti-diarrhea medications, which can decrease GI output.

Watching what you eat can affect your GI output. For example, concentrated sweets may increase output due to the high sugar content. Caffeinated foods and beverages can also increase output. All beverages should be ingested slowly because fluids empty from the stomach faster than solid food.

Oral rehydration therapy is a method used to replenish nutrients and fluids in the body that have been lost due to increased GI output. Oral rehydration therapy is accomplished with oral rehydration solutions (ORSs), which contain sodium and other substances, such as carbohydrates, potassium and bicarbonate. A suggested ORS drink contains close to a teaspoon of salt, 200 to 300m Osm, and 20 to 25 grams of glucose in one liter of liquid. The ORS may also require flavor enhancements, such as sugar-free sweetener, to enhance the flavor of the beverage. Avoid diet beverages sweetened with sorbitol or xylitol because these sweeteners are not absorbed and may stimulate stool output. ORS drinks can be purchased or made at home using recipes available on the Internet. Check with your doctor or nutrition support clinician to determine which one is right for you.

As a general rule, eat several small meals throughout the day, and drink beverages — especially ORS drinks — slowly over an extended period of time. Remember, foods tolerated by someone else may not work for you. What’s more, foods that have worked for you in the past may not work for you now. Consult with your physician or dietitian to help with your eating schedule. Meal time will be a much more enjoyable experience once you have identified the foods that work best for you.

* Adapted from The Handbook of Home Nutrition Support; Ireton-Jones, C. January, 2007, Jones and Bartlett publishers.
The HPN Connection
Using Picture Phones and the Internet to Manage Long-term HPN

by Donna Yadrich, B.S., M.P.A., C.C.R.P., and Carol E. Smith, R.N., Ph.D.

Family members and patients who manage long-term HPN are participating in a study using picture phones and the internet. The study, funded by the National Institutes of Health (NIH), is being conducted by Carol E. Smith, R.N., Ph.D. Dr. Smith is an experienced HPN researcher and a longtime member of the Oley Foundation staff. The purpose of the study is to identify effective methods for providing daily web and text message support to HPN patients and their families.

Participants in the study are loaned a picture phone and, if necessary, a computer with an internet connection. Dr. Smith and her staff then use the devices to send patient consumers and their families useful information about HPN care, including clinical advice, scheduling routines, and tips for relieving stress and worry.

The family’s opinions about the usefulness of the information and its delivery are tracked on an anonymous checklist, which is mailed to an unnamed university research center in a confidential envelope. All answers are private and only a summary of all participant responses will be reported. More than 200 people are expected to participate.

Dr. Smith has conducted similar clinical trials in the past, including a study that used educational videotaped interventions (EVIs) to guide patients through techniques for preventing HPN catheter-related infections, alleviating depression and improving communication with healthcare professionals. The findings were published in the Journal of Parenteral and Enteral Nutrition (JPEN) and LifelineLetter, the Oley newsletter, in which it was demonstrated that the EVIs significantly reduced incidents of infection over an 18-year period. EVIs also resulted in fewer hospitalizations, less depression and improved quality of life. Without the EVIs, patients’ depression returned and their problem solving ability decreased. Based on results of the EVI study, Dr. Smith has incorporated a reminder, or “booster,” section to encourage long-term use of the education materials. This new section is being provided by the picture phones and a website.

The picture phone visits are scheduled at the participant’s convenience and the website will be available for three months. The picture phone has a small screen equipped with a camera, enabling the patient and/or caregiver to view the healthcare professionals as they make their presentations. The website contains HPN management information from the Oley Foundation, as well as ideas from other patients and family members. The site also provides links to numerous third-party resources, including links to similar research studies.

To learn more about the study, call 800.776.OLEY or visit www.oley.org.
Working with Your Medical Benefits

by Linda Gravenstein

Due to the rising cost of healthcare, long-term home parenteral and enteral consumers should be prepared in the event their insurance company refuses to reimburse a claim or notifies you that you no longer have benefit coverage. Whether you are self-insured, insured by a commercial third party or insured by the government, it is imperative that you take the time to review your policy thoroughly. Although this is not necessarily fun or pleasant, it may well save your life some day. The following list provides you with tips for navigating through your health insurance policy.

1. Read each and every page of your policy. Know the limits of your coverage and keep track of your benefits. This includes not only home care, but also pharmacy prescriptions, doctor office visits, ER visits and hospitalizations.

2. If there is something in your policy that you don’t understand, ask for written clarification. Keep a copy of your written response for your records.

3. If your policy provides for a case manager, get to know the person. Often he or she is a nurse who evaluates the needs of a large number of patients; therefore it is important that you make them aware of your own personal requirements. Send a picture of yourself so he or she can put a face with your voice. Finally, ask the case manager to negotiate cost. They are there to help you get what you need, but they also want to make sure that your benefits last. In the rare instance that you cannot communicate with your case manager, ask for a new one.

4. If you have Medicare or Medicaid benefits, research which specific medical conditions are covered by your plan, then determine if your diagnosis qualifies for specific care.

5. If you are using insurance provided by your employer, read the policy inside and out. Run through different scenarios to test their coverage benefits. For example, ask yourself “What if I am disabled? What if my child is disabled? What if I retire?” Prepare yourself for any surprises that may come along.

6. Research your state’s high-risk insurance pool. Most require that you be insured in order to get insured, so do not wait until you have been dropped from your current policy and have no benefits remaining, or if you no longer qualify for government benefits.

7. Keep all premiums current.

Remember, a little knowledge can go a long way. If you do your homework, you’ll be in a better position to advocate for yourself or a loved one. ☛
Summer Time Health Tips

Protect Yourself from the Heat!
When you are spending time in the sun, a little common sense can go a long way. Keep cool, drink plenty of fluids and avoid strenuous physical activity. Limit outdoor activities that cause excessive sweating, especially in high-humidity areas. Stay cool with air conditioning, fans and cool showers. Keep skin dry and wear lightweight, loose-fitting clothing.

West Nile Virus
West Nile virus is carried by mosquitoes. Therefore the best way to avoid West Nile is to avoid mosquito-infested areas. Use bug spray that contains DEET. Wear long-sleeved tops and pants. Repair the screens in your home and protect infants with netting. Eliminate potential breeding grounds by emptying items around your yard that collect water. Keep your gutters clean and help your neighbors to do the same.

Lyme Disease
Although Lyme disease is becoming more common, it can be prevented. Taking some simple precautions can help to lessen the likelihood of being bitten by a deer tick. Wear long sleeves and pants, and tuck pants into the socks. Wear light-colored clothing so you can see ticks better. Check for ticks after an outdoor activity. If you find a tick on your person, quickly contact your physician.

Ozone Forecasts
The Department of Health warns that unhealthy levels of ozone can cause throat irritation, coughing, chest pain, shortness of breath, increased susceptibility to respiratory infection, and aggravation of asthma and other respiratory ailments. These symptoms are worsened by exercise and heavy activity. Children, the elderly and people who have underlying lung diseases, such as asthma, are at particular risk of suffering from these effects. Monitor for ozone advisories and stay inside, go to a movie or take a walk at the mall to prevent exposure to unhealthy levels of ozone.
Caregiver Corner

Did you know:

♦ Approximately 44 million American families and friends provide unpaid care to another adult, sometimes around the clock?

♦ Wives, daughters, sons, partners, fathers, nieces and brothers provide approximately 80 percent of the long-term care in the United States?

♦ Many of these individuals work outside the home and care for one or more other family members?

Below is a list of resources containing articles, tools and supportive advice designed to help the caregivers of our HPEN consumers to better manage their day-to-day activities:

National Alliance for Caregiving ................................................................. www.caregiving.org
Family Caregiver Alliance ................................................................. www.caregiver.org
National Family Caregivers Association ....................................................... www.nfcacares.org

The Nutrition Puzzler

How many of these words can you find?

ACTIVITIES OUTDOOR
ADVOCATE OZONE
CHALLENGES PARENTERAL
COMMUNICATION PICTURE PHONE
DIETITIAN REHYDRATE
FATHER SPINACH
INSURANCE SUGAR-FREE
INTERNET SUMMER
LONG-TERM SUPPORT
LYME DISEASE THERAPY
MEDICAID WEST NILE
NUTRITION ZUCCHINI
OLEY