



Complex Child E-Magazine

www.ComplexChild.com

Learning about Parenteral Nutrition and Central Lines: The Oley Foundation's Online Training Modules by Susan Agrawal

As parents of children with complex medical issues, we are used to learning new skills, medical procedures, and techniques. Most of us can typically master a new piece of medical equipment in an unbelievably short period of time. But when your child needs a central line or is beginning parenteral nutrition (abbreviated TPN, PN, or HPN), there is a lot to learn, and the learning curve is steep. Not only do you need to master site care, dressing changes, cap changes, accessing a port, preparing IV bags, adding vitamins and medications, running antibiotics, programming a pump, and other aspects of daily care, but you also have to become adept at taking vital signs and recognizing when there is a potentially serious health problem.



The Oley Foundation, a non-profit agency dedicated to providing information and enhancing the lives of people who use enteral and parenteral nutrition, has begun an online training program to help families learn to manage parenteral nutrition and central line care. While designed for adults, the majority of information in these modules is applicable to children as well. Currently, two of eight planned online modules are available for free at http://www.oley.org/Education_Module1.html.

This program was developed by Oley Trustee Cheryl Thompson, PhD, RD, CNSD, and underwritten in part by Baxter Healthcare.

The planned modules include:

- Module 1: Take Charge
- Module 2: Catheter-Associated Infection
- Module 3: Fluid Balance and Glucose Control
- Module 4: Maximizing Your Nutrition
- Module 5: Monitoring Lab Tests
- Module 6: Liver and Metabolic Bone Disease

Module 7: Catheter-Related Issues

Module 8: Getting Off HPN

Module 1: Take Charge

Module 1 is a great introduction to managing complex medical issues within the structure of our current medical system. Most significantly, it emphasizes the importance of becoming an informed consumer and taking control of your child's care. Sections include:

- Be informed
- Know your rights and responsibilities
- Find a clinician
- Enhance communication
- Seek and accept support
- Develop successful coping strategies

Links to additional external information sites are available throughout the module.

Module 2: Catheter-Associated Infection

Module 2 delves into one of the most dreaded but often preventable complications of central lines, catheter-associated infections. This module describes the different types of infections that may occur, including site, tunnel, and catheter infections. It then proceeds to describe in great detail the signs and symptoms, causes, diagnosis, prevention strategies, and treatment for each type of infection.

This module also includes extensive written materials that can be downloaded in PDF form and printed. These handouts contain information on infections in summary form, as well as general descriptions of different types of central lines, including PICCs, tunneled central lines, and ports.

Materials are easy to understand, even for someone completely new to central lines and parenteral nutrition. Additional links to more detailed information, including guidelines from professional organizations and resources, are readily available.

Integrated into this module are both the Keep Me Safe and Save that Line! campaigns, which are designed to help healthcare providers keep your child safe and his or her line infection-free.

This module is also extremely useful for nurses and other care providers who interact with your child on a daily basis. Many home care nurses or other providers have little experience with central lines and catheter-associated infections. The information provided in this module can help them to provide much more intelligent and appropriate care for your child.

Future Modules

Future modules are in the works and will hopefully be available over the next few years. Modules 5 through 7 should be extremely helpful for children on long-term parenteral nutrition to prevent, recognize, and treat complications.

For More Information

Contact the Oley Foundation for more information. The Oley Foundation provides many excellent resources for families dealing with central lines and parenteral nutrition, including resource guides, complication charts, travel information and documents, restaurant cards, medical information, forums, and an equipment exchange. They also host a yearly conference, as well as many smaller regional meetings. Membership is free to families.