

## Life With Accessories

### Common Medical Devices: What Clinicians Need to Know

Enteral feeding and IV access are commonplace in a hospital setting, but what happens if the child needs to continue enteral/parental therapy at home? Oxygen tubing and portable tanks are common, but what about a tracheostomy and a ventilator for respiratory support? You may see wires snaking out from beneath clothing or a small red light glowing through a toddler's sock. Even more accessories may be hidden, safely concealed by clothing: colostomies, ileostomies, cecostomy tubes, dialysis shunts, and vagal nerve stimulators, to name a few. What purpose do these accessories serve? Are there any activities that should be avoided? What do parents and clinicians need to know to ensure the child's safety? As the parent of a child who had never been "cordless" as well as a person with several "accessories" myself, I have the unique experience of managing medical devices from the perspective of a clinician, parent, and patient working to maintain safety and quality of life.

**Disclaimer: This information is provided for educational and informational purposes only and does not constitute medical advice. Every child's medical condition is different, and purpose, use, and handling of medical equipment needs to be confirmed by the child's physician. Clinicians are strongly encouraged to discuss and create a child-specific care plan with the family and receive physician approval before initiating services.**

Enteral Nutrition refers to nutrition that is passively delivered to some point in the GI tract via a tube. This includes NG, OG, NJ tubes (non-surgical) and G, GJ, and J tubes (surgically placed). Feeding takes place through bolus feeds, gravity feeds, and continuous pump feeds.

Gastrostomy tubes are enteral tubes that access the stomach through the abdominal wall. The style of tube can vary greatly, from a small "button" style that consists of an external valve, retention balloon, and short segment of tubing in between to a standard Foley catheter placed into the stoma and held in place with the internal balloon and secured externally with tape. This article gives lots of information about G tubes: <http://articles.complexchild.com/sept2009/00151.html>

Jejunostomy tubes are enteral feeding tubes that are placed into the jejunum rather than the stomach. Many J tubes need to be replaced by an Interventional Radiologist because they are threaded into the jejunum instead of opening where the tube first enters the intestine. However, there are some individuals who use button-style devices or other short tubes that can be replaced at home or in a doctor's office. This article gives more information about J tubes: <http://articles.complexchild.com/oct2009/00158.html>

Non-surgical feeding tubes include Nasogastric (NG), Orogastric (OG), and Naso-jejunal (NJ) tubes. NG tubes are generally used for short-term nutrition. The tube goes from the nostril down into the stomach. If a child needs an NG tube part of the time and is otherwise healthy enough to leave the hospital, the parents may learn how to remove and

replace the tube. NG tubes are easily moved out of proper position, and the caregiver needs to make sure it is in the stomach before formula is instilled. NJ tubes also enter the nostril, but pass completely through the stomach and extend to the upper small intestine. NJ tubes can stay in place longer than NG tubes can, but they are capable of being dislodged or accidentally removed. OG tubes are generally used for premature infants, because they are obligate nose breathers and even the smallest NG tube could partially obstruct the upper airway. You can find more information about NG tubes here: <http://articles.complexchild.com/aug2009/00144.html>

**Are there activity restrictions?** The new tube site may be sore for several days to a few weeks after surgery, but after the site is healed there are no restrictions regarding positions (see exception below). People often wonder if it is painful for a child to lie on his stomach with a G or J tube in place. I have both a G tube and a J tube and I've experimented with different positions and types of tubes. I found that lying on my stomach was not uncomfortable as long as my clothing was not bunched up or I was lying on top of a tube clamp. If the child has gastroesophageal reflux, he must sleep with the head of the bed raised 30 degrees, especially if feeds are given via continuous infusion pump.

**Precautions and safety** Sometimes the tube can get caught or tugged and be pulled out. Notify the child's parent/guardian immediately, because the tube tract can close in a matter of hours. If the child receives continuous feedings through a pump, he will eventually carry the pump in a small backpack. It's a good idea to slowly introduce the backpack before the child is able to pull to stand. (Empty backpack until tolerated, then backpack with ½ the weight of pump/bag, then full weight or pump itself.)

Parenteral Nutrition refers to nutrition delivered directly to the bloodstream via a CVL (Central Venous Line; including PICC, Hickman, Broviac, and implanted ports).

Central Lines end in the heart (although some femoral lines end before they get all the way up to the heart). Peripheral Lines end in small or mid-sized vessels. CVL is a generic term that can refer to any Central Venous Line, but usually is used in reference to an exterior line placed in the neck, chest, or groin. There are a limited number of sites for CVLs to be placed: Internal or External Jugular veins, Subclavian veins, and Femoral veins. All varieties of lines can have 1, 2, or 3 lumens (channels with separate attachment and outlet points).

Tunneled central lines are usually referred to by the catheter brand name or style, such as Broviac, Hickman, and Groshong. These lines are usually placed in the operating room while the child is under general anesthesia (completely asleep). The line is not only placed from the skin into the vessel and threaded into position, but a portion of the line is also tunneled under the skin, with a "cuff" (a felt-like material that encourages scar tissue formation to secure the catheter in place) at the exit site. Cuffed lines are considered "permanent" (durable, double-walled, expected to remain in place for years) and are the line of choice for patients receiving long-term nutrition, hydration, or chemotherapy.

Ports are central lines that are placed completely beneath the surface of the skin. The line tip is placed just like it is for other central lines, but the infusion end consists of a metal or plastic chamber with a silicone diaphragm on one side. The entire line is placed under the skin, and the silicone "port" is accessed by inserting a special non-coring needle through the skin into the infusion chamber. The external needle can stay in place for up to a week at a time, but when it is removed there are no external openings into the line. Ports work best for patients who need routine but not daily IV therapy, such as chemo. Between accesses, the port can remain in place with very little maintenance.

PICC lines, or Peripherally Inserted Central Catheters, are central lines that exit the skin at the upper arm rather than the chest. These lines are not anchored in place by an internal cuff, and must be held in place with sutures or a special adhesive device. PICC lines can be placed by a physician or specially trained nurse, and do not need to be inserted in the operating room. PICC lines are usually kept in place for several weeks to months, which is much longer than a peripheral line but not as long as a tunneled line or port. PICC lines are used when a child needs antibiotics or TPN for several weeks.

**Are there activity restrictions?** Central Lines must be kept clean and dry, so water activities are usually restricted. After the CVL has been placed and the area heals, there are usually no contraindications related to positioning. Since PICC lines are placed in the upper arm and must be threaded through a large vein to the heart, it is much easier for the line to irritate the inner walls of the vein, resulting in blood clots or swelling. Some physicians restrict activities like lifting and weight-bearing in the extremity with the PICC. Check with the child's doctor before encouraging activities such as crawling, heavy pushing, or pulling. The special adhesive device used with a PICC line is not painful, but a sensory-defensive child may avoid using the arm for fine motor activities. If PN is given overnight, nighttime bladder control will be delayed. Fluid and portable pumps are carried in a backpack (see enteral feeds); however, fluid volumes may be much larger, so children may be unable to carry the device as a toddler or preschooler.

**Precautions and safety** Central lines create a direct route to the bloodstream, which places the child at a greater risk for infection. Handwashing, toy and play area cleaning are required. The lines need to be kept out of the child's reach at all times. A parent, guardian, or health care provider must be present during activities at all times when the child's IV nutrition/hydration is infusing. Accidental disconnection is an emergency. For a "Keep Me Safe" poster, request or download it from here: <http://www.oley.org/documents/keepmesafe.pdf>

**For the most complete, up-to-date list of resources related to parenteral and enteral feeding, see the Oley HPEN Consumer's Guide:** <http://www.oley.org/documents/Educational%20Materials%20for%20Home%20Nutrition%20Support%20Consumers.pdf>

Ostomies An "ostomy" is a surgically-created opening between the bowel or bladder and the outside of the body. Children with mitochondrial disease have had surgical diversions created to compensate for severe muscle weakness involving the bowel and/or bladder.

An Ileostomy is an outlet created in the abdominal wall that enables stool to pass from the small intestine directly into a pouch worn on the abdomen, bypassing the large intestine and rectum. The stoma, or opening, resembles a maraschino cherry, and is generally kept covered by a collection bag and sometimes the diaper as well. The child wears an appliance made up of a strong adhesive barrier and a collection bag, which is easily emptied by the parent and changed anywhere from daily to once every several days. A colostomy is an opening from the large intestine. Ostomies are not always permanent, and many children are able to have the procedure reversed later on in life, especially children who have the procedure performed in infancy due to birth defects.

A cecostomy is a special opening surgically created in the large intestine in order to put fluid in rather than drain it out. Some children with severe constipation can have their symptoms managed by having fluid infused into the colon to help move everything along naturally rather than creating an artificial outlet. The cecostomy tube generally resembles a G-Tube or "Mickey Button," and the precautions and recommendations are the same as for that type of tube.

A vesicostomy is a procedure performed when a child has severe bladder problems. This ostomy allows urine to pass continuously from the lower abdomen, right above the pubic bone, to the outside of the body. Young children with vesicostomies often simply wear an extra-absorbent diaper instead of an appliance.

**Are there activity restrictions?** After the stoma has healed, there are generally no restrictions regarding handling, positioning, and activity. Ostomy bags may leak if the adhesive seal loosens or the bag becomes full, but the results are managed by thoroughly cleaning toys and surfaces with disinfectant, no differently than if a child's diaper leaked. All centers should follow universal precautions as directed by OSHA.

<http://articles.complexchild.com/dec2010/00258.html> "Life With and Ostomy: A Mother's Perspective"

<http://www.ostomy.org>

<http://www.ideaskids.com/parents/parentsostomy.html>

<http://www.cdc.gov/parents/infants/safety.html> CDC guidelines “Safety in the Home”\_

**Respiratory Support** Respiratory complications are common among infants and toddlers with mitochondrial diseases, and include oxygen administration, tracheostomy, and mechanical ventilation. Respiratory symptom management and illness prevention is a very important part of some children’s health care, and can be facilitated by specialized equipment.

Children who require respiratory support often receive continuous or intermittent monitoring of their pulse and respiratory rate and/or oximetry (pulse ox). Clinicians may be familiar with infant apnea monitors and pulse oximeters, as they are frequently used by premature infants with respiratory complications, in the first months to year of life. Children with mitochondrial disease may use these monitors much longer than that. Older infants or toddlers may be found to have obstructive or central apnea, decreased respiratory effort, aspiration of ingested food or drink, reflux/aspiration, or a weak cough. While most children only require intermittent monitoring, such as while sleeping, other children require constant attachment to one or more monitoring devices during sleep and play.

**Apnea/bradycardia monitor:** This monitor consists of two chest electrodes that monitor the child’s pulse and respiratory rates. This monitor is used to detect *apnea* (the absence of breathing effort for a pre-determined length of time) and *bradycardia* (the slowing of the heart rate below a set number of beats per minute). Monitors also sound an alarm for *tachycardia* (rapid heart rate) and disconnected/loose leads. The chest electrodes are usually placed on the sides of the chest, under the arms at the height of the nipples, and can be held in place with adhesive or a soft belt with a Velcro closure.

**Pulse Oximeter:** This monitor measures heart rate and blood oxygen saturation levels. Alarm parameters can be set for low O<sub>2</sub> sat, bradycardia, tachycardia, and disconnected probe/equipment malfunction. Probes are generally placed on a finger or toe. The most popular types of monitor probes are disposable adhesive probes that wrap around the finger like a Band-Aid, reusable probes that wrap around the finger and secure with a Velcro strap or self-adhering Coban wrap, and reusable probes that resemble a clothespin and clip onto a finger.

**Are there activity restrictions?** Any restrictions are generally the result of the child’s health status rather than limitations strictly posed by the equipment. Movement disrupts the accuracy of the monitor, creating false interpretations and false alarms, called artifact. Sometimes the physician will remove the monitor while an adult has continuous visual and physical contact with the child. Monitor cables are several feet long and allow the child to move short distances from the equipment, but generally an adult needs to carry the monitors so the child can explore his or her environment.

**Precautions and safety** Monitor cables are generally long enough to wrap around an active child several times, which poses a serious strangulation hazard. In order to decrease the risk of injury, thread the monitor leads under the shirt, down a pant leg, and exit at the ankle. Since O<sub>2</sub> Sat monitor probes are commonly placed on a toe or foot, cover the probe with a sock, thread the lead up the leg and exit at the back waistband and tape in place. Dressing the child in a “onesie” shirt that snaps at the crotch can deter the child from pulling off the electrodes.

Apnea monitor: basic info <http://www.medox.org/apnea.htm>

O<sub>2</sub> monitors [http://reviews.ebay.com/Pulse-Oximeter-FACTSGuide\\_W0QQugidZ10000000001217352](http://reviews.ebay.com/Pulse-Oximeter-FACTSGuide_W0QQugidZ10000000001217352)

**Oxygen** is generally given via nasal cannula, a thin tube with “prongs” that are positioned beneath and into the child’s nostrils, looped over the ears, and often threaded down the back of the child’s clothing, exiting at the waist. Most children use a large tank or electric oxygen concentrator connected to tubing that is approximately 40’ long while in their home, and the tubing can be connected to a small portable tank while outside the home. O<sub>2</sub> can be given continuously, or only during activities such as active play, feeding, and sleeping.

A tracheostomy is an artificial airway created by surgically placing a firm plastic tube through the neck and into the trachea. This is a surgical procedure, and while considered minor, it is not without risks. In most cases, a trach is placed as a last resort when a child's airway and/or breathing cannot be safely maintained by non-invasive means. The tube enters the windpipe below the vocal cords, so the child can make faint or no vocalization without the use of a special "talking valve." Bypassing the nose, pharynx, and vocal cords prevents obstruction and creates a direct opening much easier to keep free of secretions. Unfortunately, a trach also bypasses the body's built-in safety and comfort mechanisms: filtering and humidification, breath-holding, and the gag reflex, to name a few. Many children wear a special trach mask that provides humidified room air or supplementary oxygen or a small barrel-shaped attachment that conserves moisture (often referred to as an "artificial nose").

When working with a child with a trach, there should always be a responsible adult who has the training and equipment necessary to attend to the child's medical and safety needs. Infection control procedures are very important, as always. Review your facility's policies regarding handwashing, toy and facility cleaning/disinfecting, child and staff attendance during personal illness as well as flu season. The child's parents and pediatrician should discuss the potential benefits of flu, pneumonia, and RSV immunizations.

The child may require breathing support from a ventilator. Most home vents are designed to be portable, so they can operate with a rechargeable battery and are often the size and weight of a laptop computer. Many children with trachs cannot produce an effective cough, so secretions may need to be removed through suctioning the airway with a thin plastic tube and a portable suction machine.

CPAP and BiPAP are non-invasive ventilation support devices that can assist breathing via a special face mask rather than a surgical trach. Both machines provide air pressure support, with CPAP providing a constant stream of pressurized air, and BiPAP (or VPAP) senses inspiration and expiration, providing high pressure to support inspiration and then dramatically decreasing the pressure to facilitate expiration. In addition, some BiPAP/VPAP machines can sense a pause between breaths and initiate the higher pressure to stimulate inspiration. These devices are generally used during sleep.

Respiratory Treatment Devices: Here is information about three of the most popular home Respiratory Therapy treatments:

Cough assist machine <http://coughassist.respironics.com/>

Vest/chest PT: <http://www.thevest.com>

Nebulizer Treatments: <http://www.buzzle.com/articles/nebulizer-treatments-how-does-a-nebulizer-work.html>

**Conclusion** As more and more patients are treated at home by visiting nurse agencies, the number of individuals living with "accessories" is increasing. Medical devices are becoming incorporated into some peoples' daily routines. The accessory owner knows more about their own accessories than anyone else in the world! Ask questions, ask permission before touching tubes or moving bags, show respect for personal space and hygiene/infection control issues, and never forget that there's a person attached to the accessories.

## Resources

### Feeding Tubes

<http://www.feedingtubeawareness.com/index.html> Feeding Tube Awareness is a wonderful informational and supportive site created by parents, for parents of children with feeding tubes. The site is very well-organized and written from a parent's perspective, so information is easy to locate and understand.

[http://community.babycenter.com/groups/a3235/babies\\_and\\_children\\_with\\_a\\_feeding\\_tube](http://community.babycenter.com/groups/a3235/babies_and_children_with_a_feeding_tube) This online support group and message board for families has a group related to practical needs of children with all types of feeding tubes. Membership is required in order to post or answer questions, but guests are able to read most message board content.

[www.oley.org](http://www.oley.org) Oley is a non-profit organization dedicated to improving the quality of life of individuals who use home enteral and parenteral nutrition, through education, research, and emotional support. The resources found on this site range from very simple to highly technical, and are appropriate for parents, patients, family members, educators, and clinicians. Oley offers a toll-free telephone help line staffed by volunteers who can offer general suggestions and emotional support to families who need it. The Oley Foundation holds an annual conference for families and professionals. The conference location changes annually and attendance is free for consumers. The Oley Foundation offers travel and accommodation reimbursement for families who would like to attend the conference for the first time but have financial difficulties preventing them from doing so.

### Clinician Information

<http://www.mdinformatics.com/myhpn/> online learning module about home Parenteral Nutrition (part 1)

<http://www.mdinformatics.com/myhpn/part2/> learning module part 2

[http://www.oley.org/Clinician\\_Materials.html](http://www.oley.org/Clinician_Materials.html) Parenteral/Enteral Nutrition Resources for clinicians

<http://www.nutritioncare.org> the American Society for Parenteral and Enteral Nutrition, feeding tube and long-term IV therapy information for professionals

<http://complexchild.com> This e-zine is written by parents of children with special health care needs for parents of children with special needs. The articles provide important information for parents and caregivers as well as an inside perspective of life as a parent of children who are medically fragile and/or have mild to profound disabilities

[http://grey.colorado.edu/shortgut/index.php/Main\\_Page](http://grey.colorado.edu/shortgut/index.php/Main_Page) This site is intended for families of children with "short gut," a condition resulting from severe intestinal disease and subsequent surgical removal of some or all of the intestines. While this condition is not necessarily associated with Mito, the site holds a wealth of information appropriate for parents of children with any type of GI problems.

### ACCESSORY-FRIENDLY CLOTHING

<http://www.essentialwhites.com/> sells bodysuits that go up to 6T! Long-sleeved, short-sleeved, and sleeveless. Excellent prices (\$8-11 depending on size and style).

<http://www.kevinscovers.com> adjustable covers to prevent PICC line from getting caught/tugged

Gus Gear <http://www.gusgear.net> tubing covers, ostomy bag covers, custom pump bags

<http://www.medicaldignity.com> all-purpose white shirt with Velcro closures, comes in toddler, child, and adult sizes

[www.healthfullyhealing.com](http://www.healthfullyhealing.com) Pediatric Central Line Protector for kids (cloth and Velcro wrap for infants and toddlers with lines anywhere on the chest, reroutes tubing out through the back of clothing out of child's reach but accessible to

[http://www.oley.org/Peek\\_a\\_Boo.html](http://www.oley.org/Peek_a_Boo.html) children's T-shirt that allows central line to thread through a slit into a pocket on the outside of the shirt

<http://www.ableapparel.com> One-piece clothing for older children and adults

<http://www.easyaccessclothing.com/> "onesies" up to adult sizes, clothing with Velcro sides for tubing, moderate prices

<http://www.bundiebaby.com> a special onesie created specifically for infants with central lines, feeding tubes, and ostomy bags

<http://www.tummytunnels.com> iron-on patch provides access to catheter without damaging clothing

<http://great-gifts.pajamagram.com/pajama/Red%20Pajamas> one-piece cotton pajamas with snap front; infant, toddler, childrens sizes

## ENTERAL/PARENTERAL FEEDS AND ... Motor development

[MoveAround IV Buggy http://www.ivbuggy.com](http://www.ivbuggy.com) The MoveAround IV Buggy makes it easier for children to be active and mobile while receiving IV therapy at home, in the hospital, or at a clinic.

<http://www.amazon.com/Little-Tikes-Shopping-Cart/dp/B001IT0EPS> Little Tykes shopping cart: sturdy construction, tip-resistant

[Vygon Tubing http://www.vygonusa.com/lectrospiral-coiled-iv-ext-sets-pe.htm](http://www.vygonusa.com/lectrospiral-coiled-iv-ext-sets-pe.htm) Spiral IV extension tubing that expands and contracts to allow more freedom of movement -- like an old-fashioned telephone cord.

Mobility Ball (allows baby/toddlers to crawl/walk without disrupting their feedings)

Call Shawn and Pam Keener (717) 468-8367

[Backpacks Made for Kids with Pumps http://www.moog.com/products/medical-pump-systems/accessories/enteral-accessories](http://www.moog.com/products/medical-pump-systems/accessories/enteral-accessories)

Colored oral dispensers - [www.healthcarelogistics.com](http://www.healthcarelogistics.com)

## Positioning

<http://www.survivebabyreflux.com/wp-content/uploads/2010/08/FDA-Sleep-Positioners-Sept-2010.pdf> FDA warning against non-prescription infant positioning devices for use in the crib

<http://www.cpsc.gov/onsafety/2010/09/sleep-positioners-a-suffocation-risk/>

Tucker Sling <http://www.tuckerdesigns.com>

Pollywog Reflux Products An assortment of positioning devices to use with children who have special positioning needs

<http://www.pollywogbaby.com/refluxandcolic/refluxwedgesforinfantswithacidreflux.html>

Navigating the insurance reimbursement process for positioning devices: <http://www.pollywogbaby.com/refluxandcolic/insurance-reimbursement.html>

Oral motor development and feeding issues

[www.new-vis.com/fym/papers/p-feed12.htm](http://www.new-vis.com/fym/papers/p-feed12.htm) feeding therapy, oral sensory stim, oral motor skills development

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2716418/> Moving from tube to oral feeding in medically fragile nonverbal toddlers

Sensory Integration International [www.sensoryint.com](http://www.sensoryint.com)

The Sensory Processing Disorder Network (SPD Network) [www.sinetwork.org](http://www.sinetwork.org)

More helpful products on the Short Gut Wiki page: <http://grey.colorado.edu/shortgut/index.php/Products> This page lists more product suggestions for positioning, clothing, safety, suggestions

## TRACHEOSTOMY, VENTILATORS, NON-INVASIVE VENTILATION, OXYGEN

<http://www.tracheostomy.com/faq/speech.htm> Speech with a trach

<http://articles.complexchild.com/april2010/00199.html> "Being a Kid: Thriving With a Trach and Vent"

<http://www.articles.complexchild.com/july2008/00054.html> "Surviving Oxygen Therapy"

Pictures and explanations of multiple pieces of equipment: <http://www.langlanddesign.com/chase equip.html>

Pulse oximetry: overview [http://reviews.ebay.com/Pulse-Oximeter-FACTS-Guide\\_W0QQugidZ10000000001217352](http://reviews.ebay.com/Pulse-Oximeter-FACTS-Guide_W0QQugidZ10000000001217352)

Pulse Ox demo on youtube [http://wn.com/pulse\\_oximetry](http://wn.com/pulse_oximetry)

Toddlers sleep apnea

<http://www.entnet.org/ent-press/pressreleases/ASPO3.cfm>

[http://www.entlink.net/ent-press/pressreleases/COSM2003\\_10.cfm](http://www.entlink.net/ent-press/pressreleases/COSM2003_10.cfm)

<http://www.entlink.net/KidsENT/apnea.cfm>

<http://www.talkaboutsleep.com/children/> Children's sleep disorders and treatment

Dr. Bach, leading pulmonologist in the field of NIV (non-invasive ventilation) for people with neuromuscular disease

<http://www.doctorbach.com/>

<http://www.scribd.com/doc/18416065/Home-Health-Care-for-Children-Who-are-Technology-Dependent> Home Health Care for Children Who are Technology Dependent

[http://www.wheelchairnet.org/WCN\\_ProdServ/InsCaseMgrs/casemgr.html](http://www.wheelchairnet.org/WCN_ProdServ/InsCaseMgrs/casemgr.html) Seating and Mobility Resources for Case Managers

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