

# Prehospital Care of the Patient - with - Special Healthcare Needs



## Educational objectives

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This continuing education covers the more common medical devices and patient populations usually not explored in depth during an initial EMT or paramedic education. The document starts with medical devices that may be encountered at the patient's home, nursing facility, or even with a facility transfer. The second part of this education examines the special needs patient with intellectual or physical disability and ways prehospital providers can optimize their medical care. Objectives include:

- Examine the basic components and treatment consideration for the following medical devices:
  - Feeding devices
  - Longer-term indwelling venous catheters
  - Hemodialysis and peritoneal dialysis devices
  - Tracheostomies
  - Colostomies, ileostomies, and urinary catheters
  - Chest tubes and drains
- Discuss the pathophysiology and prehospital care of individuals with:
  - Cerebral palsy
  - Down syndrome
  - Intellectual disability in general
- Describe optimal methods to communicate with special needs patients.

# Table of Contents

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Educational objectives .....	1
Special Equipment and Devices .....	3
Feeding devices.....	3
Longer-term venous access devices .....	7
Hemodialysis access devices.....	11
Dialysis fistulas, grafts, and peritoneal dialysis catheters .....	11
Tracheostomies: The basics .....	15
Colostomies and ileostomies .....	17
Indwelling urinary catheters .....	18
Chest tubes and drains .....	20
Patients with Special Needs.....	23
Cerebral palsy .....	23
Down syndrome.....	28
Intellectual Disability .....	32
Communicating with the Special Needs Patient.....	33
References .....	36
Image Credit.....	38

# Special Equipment and Devices

A few of the more common medical devices found by EMS in homes and nursing facilities include:

## Feeding devices

There's several physiological reasons why a person is unable to eat food normally, including dysphagia secondary to stroke, intestinal failure, head or neck cancer, or gastrointestinal disease.<sup>1</sup>

Just as there's a wide range of reasons for not being able to eat by mouth, there is a variety of different medical devices designed to meet specific feeding needs. These devices can be temporary, such as a nasogastric tube, or permanent, like a PEG (percutaneous endoscopic gastrostomy) tube.

A percutaneous endoscopic gastrostomy tube (PEG) is placed surgically or endoscopically directly through the skin and into the epigastrium. It's usually just a simple, flexible plastic tube inserted through the skin with the tip of the tube sitting within the stomach itself. To prevent dislodgement, there are two physical "stops" on most PEG tubes:

- **An external bumper.** This is a flat plastic disk that sits on top of the skin and prevents the tube from advancing further into the stomach.
- **An internal bumper.** The internal bumper is usually a sterile water-filled balloon that prevents the tube from leaving the stomach. It looks a lot like the balloon on a foley catheter or endotracheal tube. Sterile water is used instead of saline to avoid salt crystallization on the balloon's fill port. Sometimes the internal bumper ruptures and the tube is accidentally pulled out.
- **External tubing clamp.** The external clamp is kept closed when not actively feeding or medicating.
- **End adapter.** An adapter at the end of the tube accommodates a Luer-slip (tapered tip) syringe for feeding solutions or liquid medications. It's kept capped when not in use.

### Percutaneous Endoscopic Gastrostomy Tube

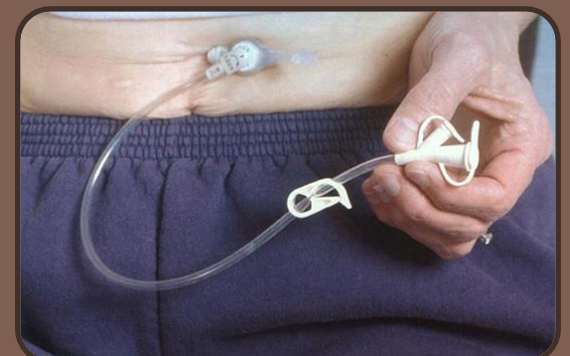
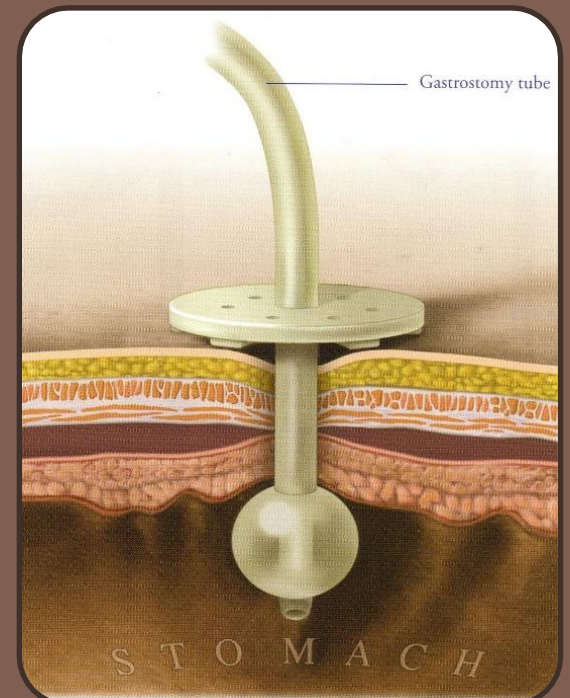


Image: PEG feeding tube with clamp. (Farrag 2019)

Children and adults who require tube feeding for more than 30 days<sup>2</sup> are more likely to receive a G-tube, either as a PEG tube (a long tube extending from the abdomen), or a skin-level button device often referred by its trade name: A “MIC-KEY®” button. Both are shown below:



**Standard Feeding Tube**



**MIC-KEY Feeding Tube**

The stoma (hole) for the tube is usually created at the hospital under local anesthesia and with guidance from an orally-inserted endoscope.<sup>1</sup> Once the tube tract has healed in about 3 to 4 weeks, the tube or button can be replaced at home by either the patient or caregiver if it becomes dislodged. It's easily replaced at home most of the time. However, EMS may be called for a feeding tube problem with some of the reasons listed below.

<b>Common Reasons EMS is Called to Transport for Feeding Tube Concerns</b>	
The gastric tube dislodges and can't be reinserted easily.	
Appears infected or is leaking.	
The tube dislodges but the stoma is still fresh and healing from surgery. When the stoma is new, the tube is usually replaced at the hospital by a specialist or surgeon.	
Abdominal pain at the stoma or increases during a feeding.	
External trauma to the tube causes internal injury to the patient.	
The caregiver does not have a replacement tube or does not feel confident in replacing it.	
The feeding tube is clogged. The incidence of clogged PEG tubes is reported to be as high as 23% to 35% <sup>2</sup>	

**Dislodged feeding tubes need to be replaced sooner rather than later.** If a feeding tube has been pulled out, it needs to be replaced within a couple of hours. Although the stoma is healed, the stoma tract will become stenotic (narrow and constrict) if something doesn't keep it open,<sup>3</sup> so this is not the patient who





*Image: Liquid meal on the go. Sometimes a person can still eat to a limited extent but may not be able to get enough nutrition unless supplemented through a gastric tube.*

should be advised to see their primary care physician in the morning or remain in the hospital's triage room for hours. In some care settings, you may find a foley catheter inserted in place of a pulled-out PEG tube to maintain the stoma diameter --- this is just a temporary solution.<sup>3</sup>

The average life span of a PEG tube is about one to two years, with tube degradation being the most common reason for tube replacement.<sup>2</sup>

### **Medicating through a gastric tube or MIC-KEY**

**button.** While we don't carry many liquid PO medications, a patient with a PEG tube or MIC-KEY® button can be given liquid acetaminophen or ibuprofen if protocol indicates this medication for treatment (fever, for example). Intact or large pieces of pills NEVER go down a feeding tube. Some people can still eat if they have a feeding tube, so always ask. The tube may be in place just to increase nutritional intake.

**If the feeding tube appears damaged, dislodged, leaks, or the surrounding skin appears infected or inflamed, do NOT use it. Transport the patient to the hospital.**

**Procedure:** Elevate the patient's head/body to at least the semi-Fowlers position (30 to 45 degrees). This prevents aspiration if the patient regurgitates. The feeding tube will need to be flushed with 20 to 50 mL of plain or sterile water before and after delivering medications to clean out the tube, so have fresh drinking water available. Saline should NOT be used since it increases sodium intake, can crystallize within the tube, and this crystallization promotes gradual clogging.<sup>2</sup>

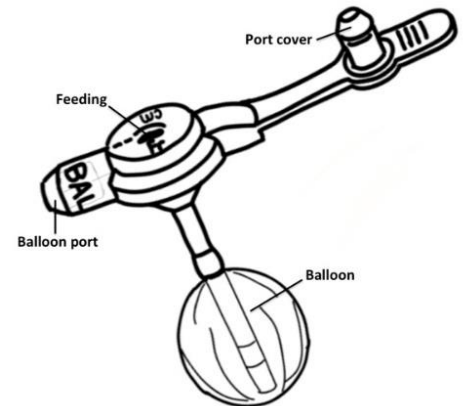
**Accessing the PEG tube is easy:** Open the cap on the largest port that reads, "FEED". Don't use the smaller balloon port. Clean the outside to avoid introducing contaminants into the stomach, and then attach a Luer-slip syringe with the plunger piece removed. The syringe will function as a funnel. Flush the tube with 20 to 50 mL of water by gravity feed, but don't force it. If the tube is clogged, don't waste time on scene troubleshooting it. Instead, just recap and transport the patient to the hospital. No matter how tempting, don't insert anything into the tube to try and unclog it.

After flushing the tube, instill the correct dose of liquid PO medication and then follow it with another 20 to 50 mL flush of water. If the patient is an infant or young child, ask the parent or caregiver about the amount of water that should be used as a flush since they have smaller stomach capacities. Liquid feedings and

medication dosing should be done as a “gravity feed” and not forced through the gastric tube in the prehospital setting. Avoid instilling excess air. If the patient’s caregiver provides reasonable instructions about access or flushing volume, follow those recommendations instead. After the final flush, reclamp the tube, clean the adapter tip, and recap.

**Button-style gastric tubes.** A MIK-KEY® button is a little more complicated. There is an extension set specifically designed for these gastric ports, and the patient’s caregiver should be able to attach it to the button.

With the extension set in place, medicating follows the same procedure as with the PEG tube.



A MIK-KEY® gastric port without an extension attached.

A MIK-KEY® gastric port with an extension set attached for instilling a feeding solution.



## Longer-term venous access devices

**Central Venous Catheters.** Some patients may have a central venous catheter (“central line”) or a PICC line (peripherally inserted central catheter) in place to provide intravenous medication or feeding solutions to help meet their nutritional needs. These access devices are used for a longer period of time than the peripheral IV catheters we insert for our prehospital use. PICC and central lines are usually inserted by physicians, mid-level practitioners, or RNs and paramedics with additional training.

The four most important things to remember about central venous catheter use:

- **ALWAYS use aseptic technique when accessing these lines.** Pathogens entering these long term catheters not only increases the risk of a serious infection, but a pathogenic biofilm or colony can form on the catheter itself over time. Don’t be the person who causes sepsis.
- **Use the clamps.** Most central venous catheters (except Groshong®) will have clamps on the line. Always clamp before removing the cap or an IV line to prevent air embolisms.
- **No flow = No go.** Don’t try to force a central venous catheter to flow by increasing pressure or using a small syringe (same effect). The catheter can shear with just 40 psi of pressure and cause an embolism. Don’t go any smaller than a 10 mL syringe to sample or infuse.
- **Don’t mix medications/fluids with TPN (total parenteral nutrition) in a single line access.** They may not be compatible. A triple lumen catheter does have three separate channels (one per port), so TPN may run in one port and medications/fluid administered in the unused distal or medial port.

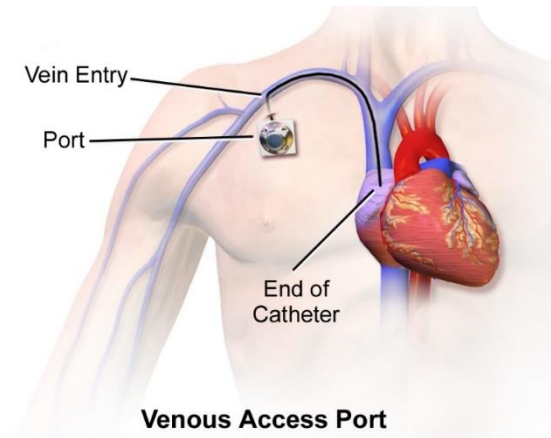
**Implanted ports.** Another venous access is called a medication, chemo, Port-A-Cath®, implanted, or Huber® port, among other names. These devices are implanted just below the skin and require the use of a special needle for access. These ports are accessed in the emergency department and other controlled patient areas using a **sterile** field, face shield, and sterile gloves. However, we may care for a patient with the port already set up for access to use, if needed.

Aseptic technique is a must when using these ports. These ports are usually placed because of an extended illness. For those whose immune system is compromised (example: patients with cancer undergoing chemotherapy), introducing a pathogen can be fatal to them.



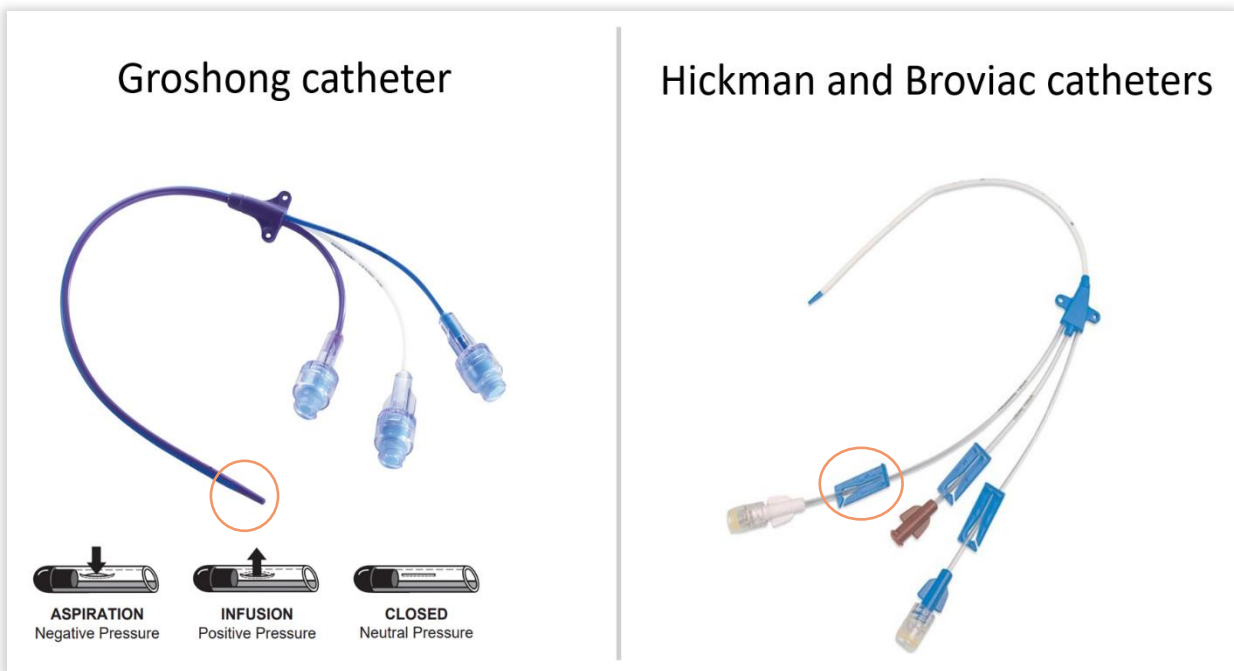
*Image: A Huber style port used for central venous access. Do not use regular needles as they will destroy the port’s base. Ports are not usually accessed in the prehospital setting in the US.*

**Variations in central venous catheters:** These catheters are usually found around the subclavian or lateral area of the chest. The lateral neck is an option as well. They may have one to three lumens available for medications or fluids. The catheter itself is usually threaded through the vena cava to near the right atrium of the heart, as shown in the illustration to the right (ports and central lines are similar in this respect).



There are three main types of central venous lines used in patients who live at home or most nursing facilities: Groshong®, Hickman®, and Broviac® catheters.

The central venous catheters basically work the same with the big difference involving the clamping system (or lack of clamps). The Broviac and Hickman catheters have external clamps on the pigtail(s) that are manually clamped and unclamped for venous access, much like an INT. The Groshong catheter is different... it does not have external clamps. Instead, the catheter wall has very precise splits that function as a valve, as shown below.

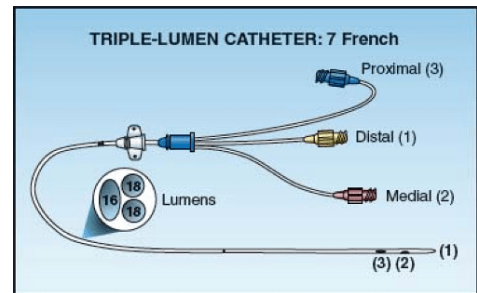


*Image: Comparing a triple-lumen Groshong catheter with a Hickman or Broviac catheter. The Groshong does not have clamps on the pigtails (circled in the Hickman/Broviac panel). Instead, splits that were manufactured near the end of the catheter will open when pressure is applied through the catheter (administering medication or fluid) or conversely, when negative pressure develops while drawing blood. If there's no pressure (e.g. INT state), then the split closes completely and effectively clamps the tubing from blood flow.*



## Administering medications/crystalloids to an adult with a central venous catheter:

- Clamp (if present) the most distal pigtail if the central line has more than one access. The hub will usually have the word “distal” imprinted on it. This catheter usually has the largest diameter lumen so you’ll be able to administer fluid with less resistance compared to the other hubs.



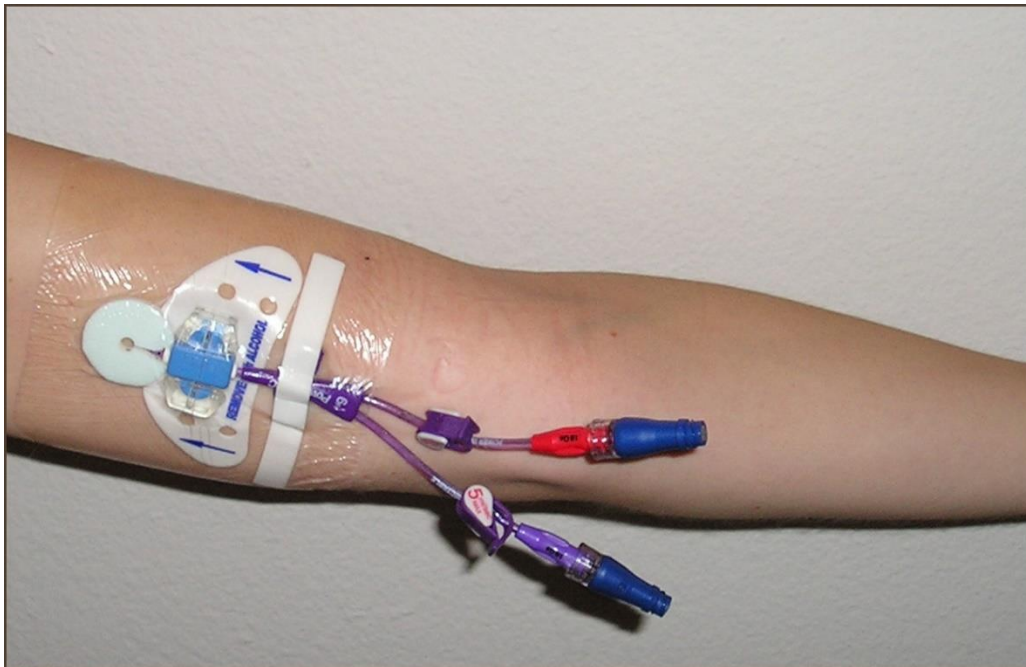
- If a cap protects the injection hub of the distal port, carefully remove it.
- Scrub the distal port injection hub with one or more alcohol preps. Don’t just wipe, but use a scrubbing motion to remove pathogens. Always maintain cleanliness.
- Since we don’t know if the line has heparin in it, attach a 10 mL syringe and withdraw 10 mL of blood from the access port. You’re going to assume it has been heparinized and you don’t want to force that medication into the patient’s circulatory system.
  - If unable to withdraw blood, ask the patient to raise his or her arm back to help reposition the tip of the catheter.
  - If still unable to draw blood, clamp the tubing (if a clamp is present), detach the syringe, and recap the port. This port cannot be used.
  - NEVER force fluid into a port with a flush, pressure bag, or by any other mechanism.
- After withdrawing the blood, waste the syringe and attach a 10 mL normal saline flush or an IV line of a crystalloid solution to the port. Make sure the access port and IV line hub do not become contaminated during the process.
- Confirm fluid flow with a slow rate to begin with (not “wide open”). If free fluid flow is present and does not cause discomfort to the patient or signs of infiltration, continue using the port as you would with any peripheral access.
  - Do NOT use a pressure bag or other device to increase the flow rate as this can shear the catheter itself.
  - Remember that the catheter sits by the right atrium of the heart. Don’t push a medication rapidly unless specifically indicated (adenosine, for example).
  - If the patient reports pain or discomfort, immediately stop the infusion and clamp the pigtail. Let the receiving nurse or physician know about the access discomfort.



- Medications can be infused through a cleaned medication port on your fluid line or by using the medial or proximal port of the central venous access. If you decide to use the medial or proximal port of the central line, be sure to follow the same instructions for cleaning and blood waste. Central line access is not a rapid process.

Under our protocol, an advanced EMT (AEMT) or paramedic can access central venous lines and PICC lines for fluid and medication needs. However, if the access is for dialysis (described later), this cannot be used for regular prehospital needs. The patient needs to be in peri-cardiac arrest or cardiac arrest to access dialysis ports since they are so crucial to the patient's need for regular dialysis.

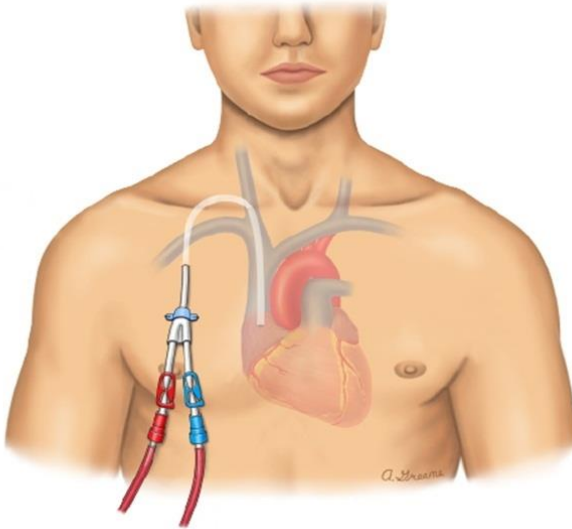
If the patient has a PICC line (shown below), access is the same as described for a central venous access. PICC lines can be single, double, or triple lumen, just like central lines. Use the distal port for prehospital access.



*Image: PICC line used for long term venous access. Treat these with the same cleanliness and respect as a central venous catheter (central line) to prevent infection or damage to the catheter.*

## Hemodialysis access devices

**Hemodialysis catheters:** There are several types of dialysis access catheters, including Tesio® and other



brands. Externally, they appear the same though, usually exposing two large diameter pigtails with a red hub and a blue hub. Unlike Groshong central venous catheters, these are clamped. The larger diameter catheter handles the massive volume of blood filtered during a dialysis session.

These catheters may be found in the subclavian area, the neck, or even uncommonly in the femoral area. They are usually used as a temporary dialysis access site until the fistula or graft in the arm is healed enough (“matured”) for dialysis use.

Since these catheters are the patient’s lifeline, they should not be used for routine or even serious fluid or medication needs. Start a peripheral IV instead. Under our protocols, hemodialysis catheters can only be used during cardiac arrest or peri-arrest (at the brink of cardiac arrest). If these catheters must be accessed, use the blue clamped side for pre-hospital treatment. You **MUST** withdraw 10 mL of waste blood before use since these catheters are heavily heparinized to prevent clotting.

## Dialysis fistulas, grafts, and peritoneal dialysis catheters

Patients who have been going to their hemodialysis sessions for a while usually have a surgically-created fistula or graft in their arm, or even less commonly their thigh. The graft or fistula allows them to continue



dialysis without the high risk of infection that’s associated with the temporary dialysis catheter at the chest or neck.

During the hemodialysis session at the hospital or dialysis center, a dialysis nurse or biomedical technician inserts two apheresis needles into the fistula or graft using sterile technique. One needle is connected to tubing that brings blood into the dialysis machine while the other needle allows “cleaned” blood to return from the dialysis machine

back into the patient. Regular needles found on the ambulance should not be used on a fistula or graft. Hemodialysis is usually performed three times a week.

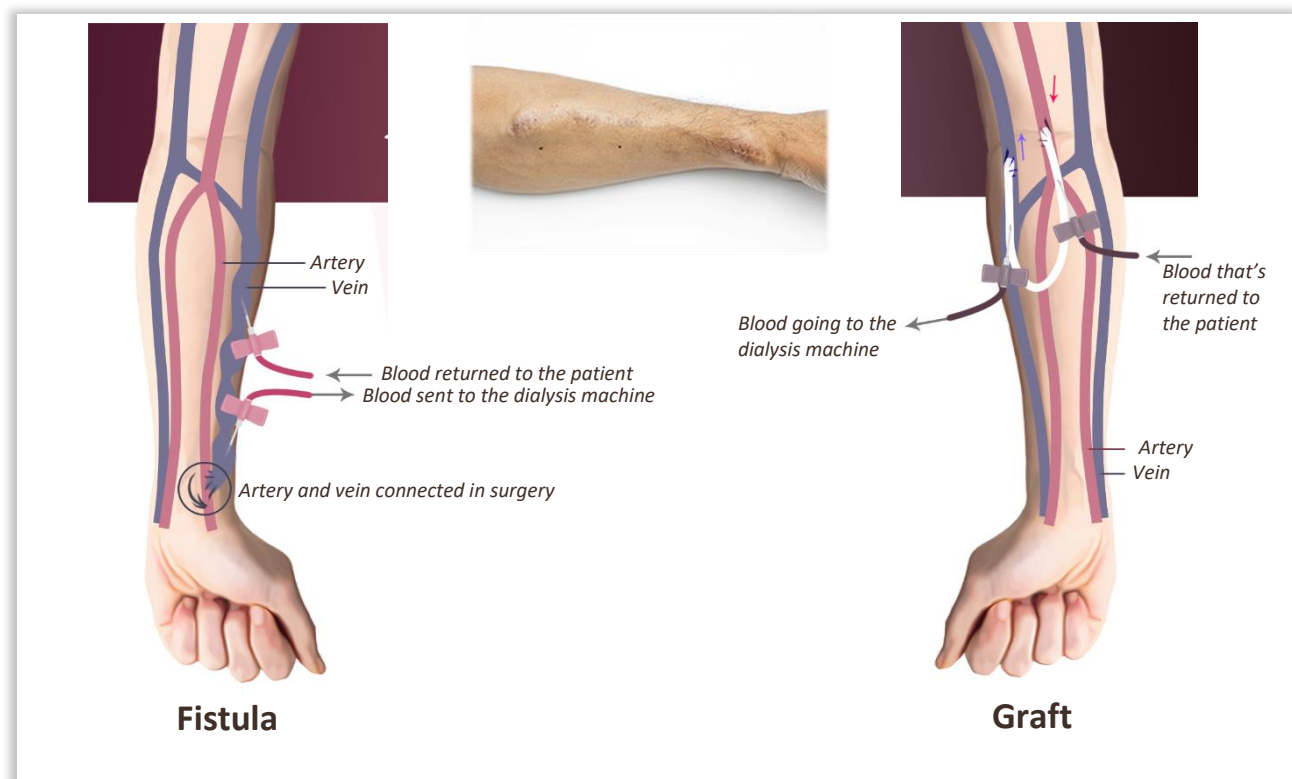
After a dialysis session, pressure is applied over the puncture sites for about 10 minutes after apheresis needle removal. Heparin was added to the blood to prevent it from clotting during dialysis, so it takes a little longer for the puncture sites to clot and rebleeding sometimes occurs after the patient returns home.



*Inserting an apheresis needle into a fistula.*

When this happens, the patient knows to hold pressure over the puncture site, but sometimes this isn't effective enough and they need to be transported to the hospital. There could be a problem with clotting factors in the blood or the puncture site itself could be damaged, leaving a bigger hole than expected from just the apheresis needle.

Even though the site is bleeding, use **only direct pressure** to stop or slow the bleeding. Direct pressure may need to be continued through the duration of transport. Never apply an extremity tourniquet to try and stop the bleed. If you do, you'll risk forming clots in the graft or fistula itself and render them unusable... ever. If the graft or fistula clots and cannot be "unclogged", the patient may have to undergo surgery for another fistula or graft in the other arm or leg and have a temporary dialysis access placed in the chest as well.





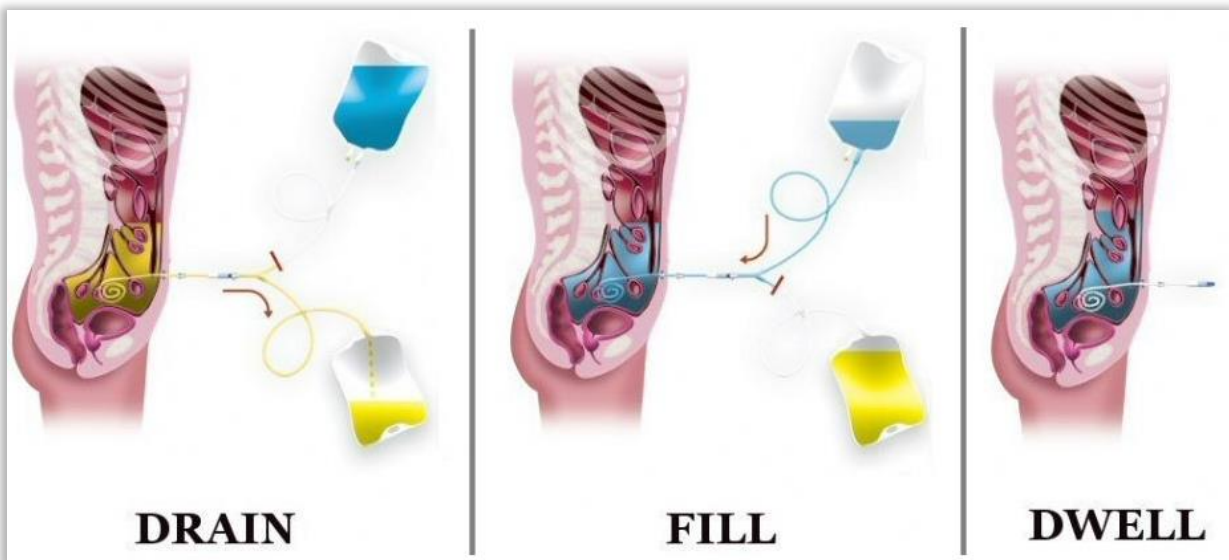
When caring for the dialysis patient, part of the assessment includes examining the fistula/graft for signs of infection and feeling for pulsing or vibration, which confirms blood flow. If you don't feel anything over the graft, blood flow may be occluded and this needs to be relayed to the receiving healthcare provider. Never take a blood pressure on the same arm of an active fistula or graft site. When in doubt, ask the patient where a blood pressure is best. And be sure to avoid starting an IV on the arm with an active fistula or graft.

**Peritoneal dialysis.** Peritoneal dialysis does not require direct blood transport from the patient to the machine. Instead of using a graft or fistula, dialysis occurs in the abdominal cavity using the peritoneal membrane as a fluid filter.

With peritoneal dialysis, dialysis fluid (called dialysate) is infused into the peritoneal cavity through a surgically-implanted catheter. The fluid is held (dwells) within the abdomen for a prescribed period of time. This allows excess water and waste products to diffuse from the blood through the peritoneal membrane and then into the dialysate on the other side. So basically, the lining of the abdomen (the peritoneum) acts as a membrane to allow excess fluids and waste products to pass from the bloodstream into the dialysate.



*Image: Peritoneal dialysis catheter with attached tubing.*



*Image: The abdomen is drained of fluid, filled with fresh dialysate, and then allowed to dwell for a prescribed duration. Once the dwell time has been reached, the fluid is drained out and refilled with fresh dialysate. This cycle continues about four to five times a day at home manually or can be automated by machine (cycler) while sleeping.*

When the dwell session is done, the "used" dialysate can then be drained out of the abdomen (called an exchange) into a container and then disposed of into a regular sewer-connected drain. This used fluid contains the excess fluid and waste that would have normally been eliminated in the urine. The peritoneal cavity is then filled again with fresh dialysate, and the process starts again.

The process may be done manually (without a machine) four to five times during the day by infusing the fluid into the abdomen and later allowing it to run out by gravity. The process of connecting the bag of new dialysis fluid, emptying, and filling for each exchange takes 30 to 40 minutes when done manually. The exchange may also be done using a machine (called a cycler). This is what most patients do. In this case, the fluid exchanges are done automatically while the patient sleeps, and, because the person's catheter is already connected to the machine by a long tube, each exchange takes less time. When using a cycler, peritoneal dialysis usually continues for about 8 to 10 hours.

EMS may be called for abdominal pain or possible hernia from peritoneal dialysis, which are the two more common complications. The patient may report abnormal appearing dialysate fluid from his or her abdomen; this could suggest a serious problem ranging from infection to bleeding. An example of abnormal dialysate fluid is shown below. Normal exiting dialysate should be clear and in light shades of yellow.

## Peritoneal Dialysis Fluid Appearance



### Cloudy:

Peritonitis  
Intraperitoneal disease (appendicitis, cholecystitis, bowel ischemia)  
Retroperitoneal disease (pancreatitis, renal cell carcinoma)  
Drugs (vancomycin, amphotericin B)  
Allergic reaction (increased eosinophils)



### Bloody (hemoperitoneum):

Coagulopathy  
Retrograde menstruation  
Ovulation  
Strenuous exercise  
Ovarian cyst rupture  
Adhesions  
Catheter-associated trauma



### Chylous:

High triglycerides  
Lymphatic obstruction  
Trauma  
Abdominal lymphomas  
Pancreatitis  
Drugs (calcium channel blockers)



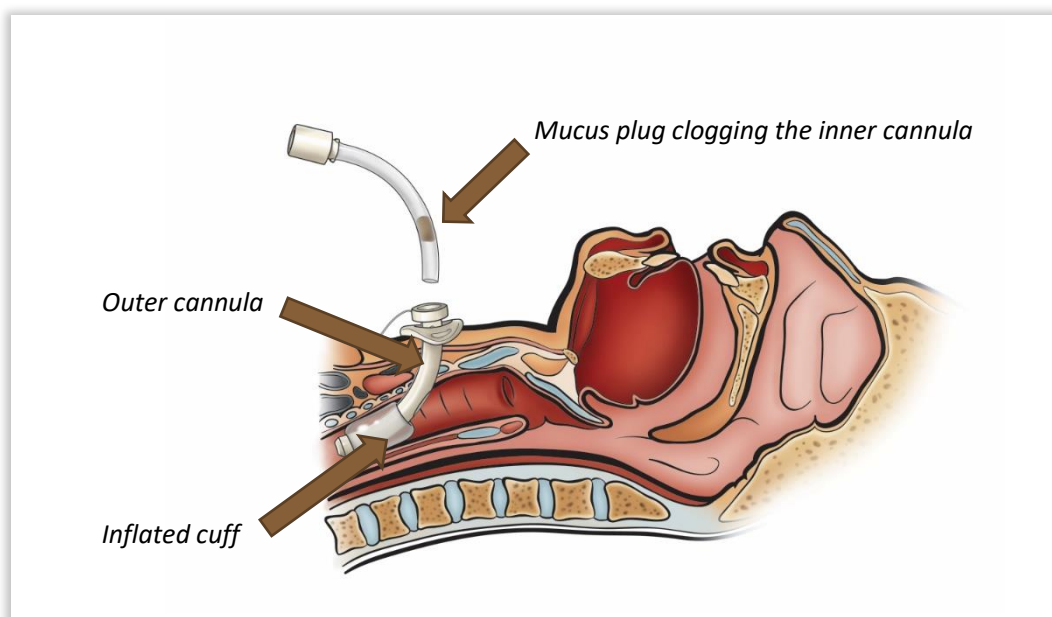
### Normal

*Image source: Dr. Gerald Diaz*

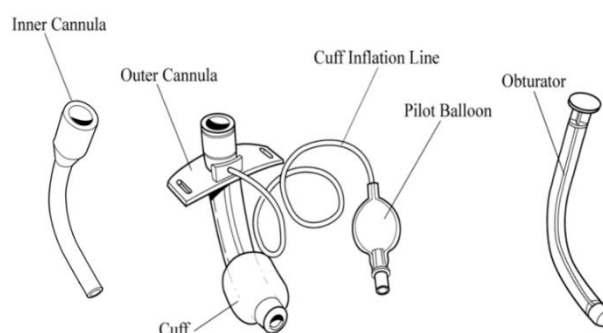
## Tracheostomies: The basics

For patients with a tracheostomy, the most common problem we'll see is from a mucus plug that either the patient, caregiver, or nursing staff were unable to remove using suction. These patients may be ventilated mechanically with a ventilator or may be able to breathe spontaneously with or without oxygen supplementation. Communication can be difficult unless the patient has a speaking valve, so rely heavily on the caregiver for information. However, don't ignore the fact that the patient can still hear and understand what you are saying. If non-emergent, consent to treatment is important.

If EMS is called for a mucus plug, one person should assess the tracheostomy and see if the patient can be ventilated. The other should learn what type of tracheostomy tube is in place and prepare for sterile suctioning. Specifically, learn whether it is a single cannula or dual cannula tube.



A dual cannula has a separate inner cannula that can usually be removed with a twist and cleaned, and the outer cannula remains in place to maintain the surgical opening. It's the most common one used in adults and is shown in the illustration above. On the other hand, a single cannula tracheostomy is just one piece (*outer cannula only*). Removing it leaves a stoma without any structural support except for healed tissue. In most cases, both styles have a cuff that's filled with air to hold the cannula in place, just like an endotracheal tube.



Parts of a common tracheostomy configuration: Outer cannula, inner cannula, and the temporary obturator.

Usually, sterile suction with a little sterile saline can remove a mucus plug without having to pull out the cannula with either style.

### Important prehospital care tips for tracheostomies:

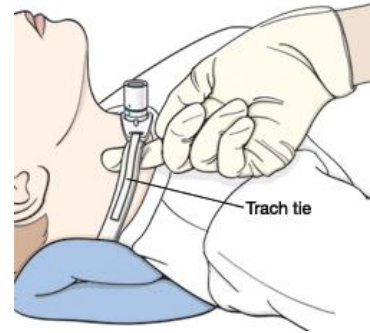
- Use sterile suction technique to remove mucus plugs. A tracheostomy bypasses some of the normal air-filtering structures from the nose to the larynx. Shortcuts in technique (laziness) can lead to severe respiratory infection. If this doesn't bother you... find a different profession.
- To prevent tracheal injury, don't exceed 120 mmHg of suction in the adult. Use lower limits for pediatrics.
- If possible, position the patient with the head of the bed elevated and let him or her know what you are doing at every step. Place a sheet or towel on the patient's chest to prevent secretions from soaking the patient's clothing. This is common courtesy.
- If the patient has a speaking valve and difficulty breathing, remove it. Did a caregiver accidentally leave the cuff inflated? If the cuff is inflated, the patient is unable to exhale and this leads to suffocation. Just deflate the cuff, leave the speaking valve off, and oxygenate the patient to recover lost ground.
- If the tracheostomy has a dual cannula and sterile suctioning does not clear it, is the inner cannula disposable? If so, does the caregiver have a replacement or will it have to be cleaned out with sterile water and a tracheostomy brush before it's placed back into the outer cannula? The patient can breathe or be ventilated through the outer cannula if needed while the inner one is cleaned or a replacement found by the caregiver.
- If the tracheostomy tube "completely came out" (*outer cannula*): Remove the inner cannula (*if present*) from a cleaned or replacement outer cannula. Put it aside but within reach. Insert the solid obturator into the outer cannula to use as a guide. Gently insert the outer cannula/obturator back into the stoma and then remove the obturator. Someone needs to hold the outer cannula's neck plate gently against the skin until new trach ties secure the device. Inflate the pilot cuff with air, insert the inner cannula (*if present*), and ventilate or oxygenate the patient.
- Whenever the outer cannula is removed, deflate the cuff balloon using a syringe to prevent stoma injury. Once reinserted, be sure to reinflate the pilot balloon to prevent aspiration. Don't inflate the cuff if the patient wants to use his or her speaking valve.



*Image: A speaking valve. It can be found in different colors (but not red... that's a cap). The one common feature with most types is the spoke-like pattern across the face of the device. This is how you'll know it's a speaking valve versus anything else.*



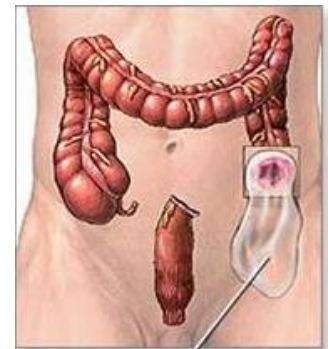
- Always have help with you. For example, if the tracheostomy cannula is not secured with ties, someone needs to hold the neck plate gently against the skin until it can be secured. Ventilate the patient if they need assistance. Oxygenate.
- Tracheostomy ties should be loose enough to allow only a finger to slip under the tie.
- Clearing the tracheostomy patient's airway is not a "load and run to the safety of my ambulance" event. You have your airway bag with you - Take care of the patient immediately to prevent worsening hypoxia.



## Colostomies and ileostomies

Colostomies and ileostomies are surgically-created abdominal openings that help people manage fecal excretion problems caused by paralysis, trauma, smooth muscle disorders/inflammation, anatomical abnormalities, or from cancer. For some reason, they are unable to eliminate stool through the rectal opening. Not many EMS calls will have a chief complaint directly involved with one of these devices unless related to systemic infection or hernia development. Displacement or collection bag leakage is usually handled at the patient's home or nursing facility.

But, we may respond for other unrelated reasons such as chest pain, dyspnea, or altered mental status. It's important that we don't damage the device by accidentally puncturing or tearing it, and we should know what the signs of infection look like through the transparent window.



**Colostomy bag**

**Colostomy.** A colostomy involves creating a surgical opening (*stoma*) in the abdomen. The diseased or non-functional large intestine or colon is removed or bypassed, and the remaining healthy portion of it is drawn towards the stoma and sutured in place. A disposable plastic bag with a coated cardboard or plastic base is secured over the stoma to allow for fecal collection and removal. The colostomy bag has a central hole in the base that is cut to size by the nurse or caregiver and is secured to the skin using an adhesive backing.



*A colostomy stoma. It should protrude about one inch from the abdominal wall, be moist, and have a beefy red color. Pale, dark, dry, or sunken-in is a problem.*



*An infected stoma*

Like any other opening in the body, the stoma can become infected. This is something that can be recognized during our patient assessment. A healthy stoma is living tissue. It should protrude from the abdomen by about an inch for an adult, have a dark pink to deep red color, and the surrounding skin shouldn't appear inflamed/infected. A dry stoma or one that's sunken-in is not normal. While some tissue protrusion is normal, obvious herniation needs a physician assessment.

**Ileostomy.** An ileostomy is a lot like a colostomy except that the small intestine is drawn into the stoma instead. The same rules of infection still apply, but the contents in the collection bag will appear more fluidlike with a different color compared to a colostomy further down the tract. A jejunostomy also diverts the small intestine, but more specifically at the wall of the jejunum.

A colostomy can be reversed in some cases. Some colostomies involving the most distal portion of the large intestine may not have a collection bag, but instead the stoma is “capped” and the patient can irrigate out the fecal matter several times a day.

The biggest take-home for EMS is to be aware of the collection bag to avoid damaging it, and to consider that infection can be serious if left untreated.



*Zoey Wright winning her class at her first body building show in September 2015. Ulcerative colitis was the cause for her ileostomy.*

## Indwelling urinary catheters

An indwelling urinary catheter is also called a “foley catheter”. It was named after Dr. Frederic Foley, an American surgeon who designed the original catheter in 1929.

A flexible tube is passed through the urethra using aseptic technique and the distal end sits inside of the bladder to continuously drain urine. These can also be inserted through a surgical incision into the bladder (*suprapubic catheter*) if urethral insertion is not an option. A balloon that sits close to the distal end is filled with sterile water after insertion, and like a gastric feeding tube, acts as an internal bumper to prevent the foley from falling out.



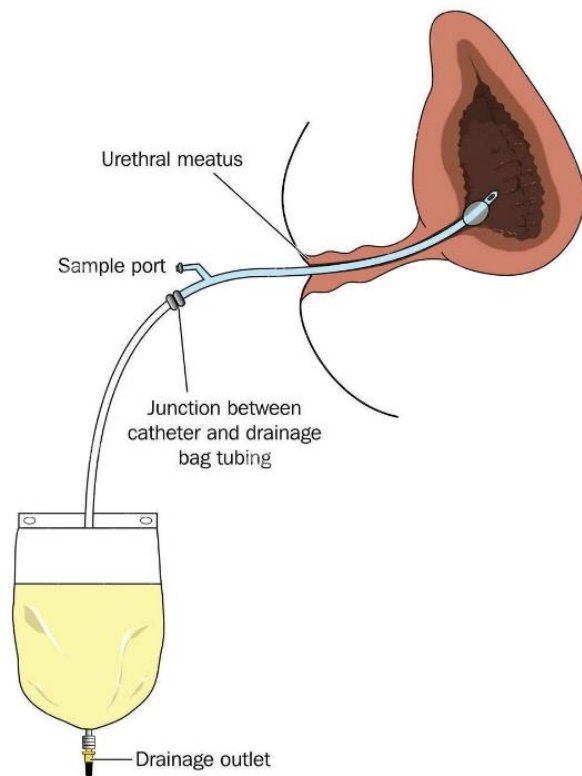
*A suprapubic catheter*

Foley catheters *used* to be very common, even in the emergency department. Paramedics with a few decades of experience behind them probably remember when *anyone* received prehospital furosemide (*Lasix*, a *potent diuretic*), they almost always got a foley in the ED to avoid frequent trips to the restroom or bedpan use. But with the increased risk of urinary tract infections and antibiotic-resistant pathogens, foley catheters are now ordered only when indicated.

However, for some patients with severe weakness, trauma, or other conditions that prevent them from using a toilet, a foley catheter may be necessary to prevent urinary retention and to monitor urinary output.

While we don't insert foley catheters on scene, EMS is obligated to assess the urinary output for signs suggesting dehydration, skeletal muscle disorder, or infection that might "clue in" to the cause of the

patient's signs and symptoms. We also need to manage the existing foley catheter to not cause harm to the patient or damage the device.



Urine output should be clear, not cloudy. The presence of any particulates (*small chunks*) or blood clots needs to be reported both to the receiving staff and in your report. A urinary tract infection is the most common cause of sepsis, so be sure to obtain a temperature for any patient with abnormal-appearing urine in their foley collection bag.

A question to ask the patient or caregiver on scene: When was the bag last emptied? This information will help determine urinary output, which should be at least 0.5 mL per kilogram of body weight per hour in the adult. This information can be used to consider any fluid deficits and is valuable to the hospital's receiving staff.

When transporting these patients, don't allow urine in the collection bag to backflow into the bladder. If the collection bag needs to be elevated above the level of the pelvis, clamp the tubing first. Be sure to release the clamp once the bag can be lowered below the level of the patient's bladder.

Due to the vascular nature of the genitourinary tract, a "pulled out foley" can be an emergency if the balloon was fully inflated.

## Chest tubes and drains

Chest tubes are normally found in acute care settings. But, we are seeing more interfacility transfers that may have a chest tube in place and need safe transport by ambulance. The next few pages review chest tube and collection device management for interfacility transfers but is not a comprehensive source of information. It's just enough for safe transport and care of these patients.

A chest tube is inserted to help displace the positive pressure air or blood that accumulated in the pleural space, which caused a pneumothorax, hemothorax, or hemopneumothorax. The distal end of the chest tube



is then attached to the collection device that sits below the level of the chest tube insertion site. Blood and air drains into the collection device, usually with the assistance of low pressure, continuous suction from a regulated wall suction unit or just by gravity.

The drainage unit is a single-patient use plastic container with multiple columns, and the number and type of columns differ depending on whether it's a dry suction/dry seal, dry suction/wet seal, or wet suction/wet seal device.

**Assess the chest tube.** Before leaving the facility, assess the patient's chest tube while you still have the physician within reach. It should be sutured to the skin with a "string" wrapped around the tube that's close to the skin. Don't remove this excess suture material... it'll be used like a purse string to help close the incision once the tube is removed by the physician.

Dressing may surround the tube. Tape or an occlusive dressing should secure a portion of the tube to the body. If you're concerned that the tube is not secured well enough for transport, ask if additional tape may be used to prevent accidental dislodgement.

A few more things to check before transferring the patient to your stretcher:

- Do you hear any air leaks at the incision site, such as a whistling sound?





- Examine the incision site, making sure that no pilot eyes (holes at the side of the tube as shown in the image to the right) are visible. If any are seen above skin level, this means the tube has been pulled out and the holes will allow air to enter into the pleural space. The physician on scene will need to evaluate and reposition the chest tube... don't just push it back in and call it good.
- Is there a lot of subcutaneous emphysema surrounding the incision site? A little can be expected, but a lot is abnormal.



**Assess your patient and vital signs.** Do you have signs and symptoms of a pneumothorax even with the chest tube in place? Is your patient comfortable enough for travel? Is the chest tube draining?

**Assess the collection system.** Lubbock area hospitals and freestanding emergency centers use several brands of chest tube drainage systems, including Pleur-evac®, Atrium®, and Heimlich Chest Drain Valves. The Pleur-evac® and Atrium® units are functionally similar. For our short-distance transport purposes, the key points to remember with these systems:

- The chest drainage system usually does not need suction for our short transports. Leave the suction stopcock open if using gravity drain (*and if this valve is present on the suction tubing*). Do not clamp the chest tube tubing.
- If suction *is* ordered, adjust the suction strength to at least 80 psi.
- Keep the collection system **below** the level of the chest tube insertion site **at all times**.
- Don't allow the collection system to tip over. If the system does accidentally tip over, bring it back upright and be sure to let the receiving nurse or physician know what happened.
- Don't "milk" the chest tube tubing to dislodge clots. The pressure generated within the tube can be high enough to cause injury to the chest.
- Never clamp the tubing. This can cause a tension pneumothorax.
- If the chest tube is pulled out for any reason, immediately apply a VENTED occlusive (Halo) dressing or a seal with just three sides taped down over the chest tube insertion site. You don't want to completely seal it off, otherwise, you just created a tension pneumothorax.



**Heimlich or flutter valves.** Heimlich valves are a lot simpler to manage. They are short (about 5 inches long), stay close to the patient, and do not have a temperamental, bulky, fluid-filled container to monitor. They were first introduced in 1965 by thoracic surgeon Dr. Henry Heimlich (same one attributed to the Heimlich Maneuver)<sup>4</sup> but are still not a mainstay device in the hospital setting. You may find patients with this valve at home or in freestanding emergency centers.

The Heimlich valve system connects to the chest tube and allows fluid and air to pass in one direction only. Regulated suction can be attached to it if necessary, but otherwise is a gravity-fed drain. The valve drains into a plastic bag that can be held at any level, allowing the patient undergoing chest drainage to be ambulatory simply by carrying the bag with him or her.<sup>4</sup>



*Image: A Heimlich-style valve (Gogakos 2015)*

After initial placement, a distinct “flutter” sound can be heard when air passes through the valve, ensuring that the device is working properly. Absence of the sound accompanied with no movement of the rubber sleeve means that no air is passing through the valve. This suggests that either the pneumothorax is resolved or instead, the chest tube itself is clogged and not allowing air to pass through. Or, the valve itself was

connected to the chest tube backwards with the outlet side hooked into the tubing.<sup>4</sup> Assess your patient to determine if no flutter sound is a good sign (resolution of the pneumothorax) or one suggesting a problem (clog or the device was inserted incorrectly).



*A Heimlich-style collection system*

The important EMS management tip for these devices is to prevent kinked tubing, avoid clamps, and don't allow either the device or the tubing to be pulled. Use a piece of tape to secure the end of the device to the patient if needed and if there's a collection bag, be sure it's well supported.

# Patients with Special Needs

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Besides special medical devices, EMS providers also need to be aware of some of the more common genetically acquired or environmentally-induced conditions that may need prehospital care and transport. Two conditions are described (cerebral palsy and Down syndrome) as representative examples. However, there's hundreds of other conditions with genetic or environmental sources that would also require special communication and handling needs. Focusing on cerebral palsy and Down syndrome offers a groundwork for assessment and care that could be transferred to many other conditions as well.

## Cerebral palsy

Over 100 years ago, a name was given to a large group of unrelated movement disorders that appeared to involve "brain paralysis": Cerebral palsy (CP). During that time, it didn't matter what caused the disorders... whether the *so-called* brain paralysis was from trauma, a medical cause, or even a parasite. The patient could have a lesion on the spine that caused paralysis or a traumatic spinal cord injury, and this would be lumped into the "cerebral palsy" category. In effect, the diagnosis of "cerebral palsy" was used more as an umbrella term to describe ALL early childhood neuromotor abnormalities.

Today's definition of cerebral palsy is more specific: Cerebral palsy involves a brain lesion, and only a brain lesion. It does not include any deficits, injury, or malformations of the spinal cord or skeletal muscle. The problem lies in brain signaling to the spinal cord and muscle. The brain is unable to send the appropriate signals to instruct muscles to relax and contract, even though the muscles would otherwise be able to do so. While there may be a genetic cause in a few patients, environmental exposure in-utero or shortly after birth appear to contribute to most cases.



Dr. William J. Little

Cerebral palsy was first described by Dr. William John Little in 1862, and was coined "Little's Disease" for decades. He did not have cerebral palsy himself, but instead developed an interest in lower extremity mobility impairments after suffering the effects of poliomyelitis (*polio*) to his left leg and foot.

Later in 1990, an international conference in Brioni, Yugoslavia brought together researchers and physicians who eventually agreed upon a more specific definition of cerebral palsy: *"An umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development"*.<sup>5</sup>

In 2006, it was further defined as: “...a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain...”<sup>6</sup>

With these new and evolving definitions in place, the specific needs of this population could now be addressed, leading to better treatment, therapy, and care. While cerebral palsy can be caused by genetics, fetal environmental exposures, or even trauma (prenatally, during birth, or shortly after), by definition it is not a condition that involves new-onset trauma or exposure as older children or adults. An adult is not diagnosed with new-onset cerebral palsy when he or she develops a brain lesion. However, a person with cerebral palsy may live a productive life through adolescence and adulthood, depending on the degree of affect. A person with cerebral palsy may or may not have intellectual deficit --- some may have baseline cognitive challenges while others may be geniuses.

**Epidemiology.** Cerebral palsy is the most common motor disability in childhood, with the Centers for Disease Control and Prevention (CDC) estimating an average of 1 in 345 children in the U.S. having CP.<sup>7</sup> This ratio has remained virtually the same for over 40 years. In the city of Lubbock alone (60,055 children under 18 years old, per 2019 data)<sup>8</sup>, this suggests we could potentially care for 174 children with some degree of cerebral palsy. Spastic cerebral palsy is the most common type and is associated with injury to the pyramidal tracts in the brain. In this case, the skeletal muscles contract more easily due to hyperactive reflexes. This results in stiff, jerky movements and increased deep tendon reflexes, even though the limbs themselves usually appear very underdeveloped.

**Etiology.** Cerebral palsy (CP) affects a person’s ability to move and maintain balance and posture.<sup>7</sup> This disorder usually develops during the fetal stage from several possible causes, such as maternal exposure to the herpes simplex virus, rubella infection, prenatal hypoxia, brain injury, maternal infection, an Rh (*Rhesus factor*) incompatibility between the mother and fetus, among many other suspected factors.

Brain damage leading to CP can happen before birth, during birth, within a month post-partum, or even very rarely during the first years of a child’s life while the brain is still developing. *Congenital CP* refers to the brain damage that occurs before or during birth, and represents most of the cerebral palsy cases (85% to 90%).<sup>9</sup> A small percentage of CP is caused by brain damage that occurs 28 days or more after birth (*acquired CP*), and is usually associated with an infection, such as meningitis or even head injury.<sup>9</sup> Prematurity is a major risk factor for cerebral palsy.

**Signs and symptoms.** As the child grows, the brain lesions that caused cerebral palsy do not grow themselves. But, their effect on motor skills, balance, and posture can affect the child’s signs and symptoms. The degree





of effect can be mild (*awkward gait or a need for limb braces*) to severe, with the child in this case bedridden and requiring full care and assistive devices for daily living.

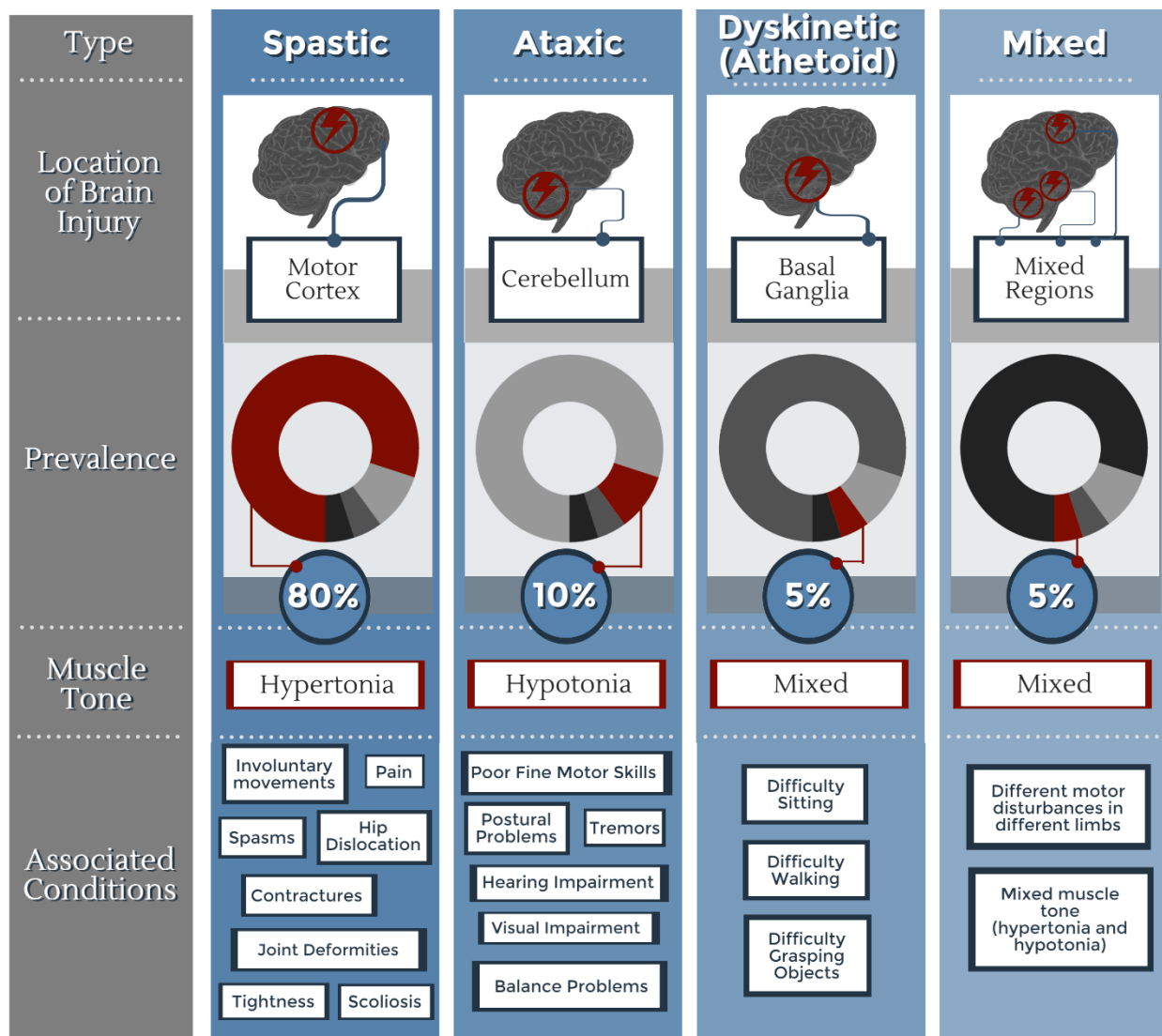
Severe cases affect about 25% of all those diagnosed with cerebral palsy. However, all diagnosed with CP have some degree of difficulty with movement and posture. These disorders usually involve stiff muscles (*spasticity, affecting about 80% of those with CP*)<sup>9</sup>, uncontrollable movements (*dyskinesia*), and/or poor balance and coordination (*ataxia*).

Cerebral palsy not only affects motion, but is usually associated with one or more of the conditions listed below:<sup>9</sup>

- Intellectual disability. Approximately 30 to 50% of those with cerebral palsy have mental retardation.<sup>10,11</sup> Others may be completely unaffected cognitively, but have difficulty hearing or speaking that masks their true intellect.
- Seizures affect 15 to 60% of all diagnosed with cerebral palsy. In some, multiple seizures may occur daily, even when managed with medication.
- Problems with vision, hearing, or speech.
- Changes in the spine (*example: scoliosis*).
- Joint problems, such as contractures to the hands and/or feet.
- Excessive oral secretions.
- Hip adduction (*shown in image to the right*) or may be prone to developing other serious conditions, such as hip subluxation or hip dislocation.
- Weak head control. This is particularly important with any significant trauma.



The chart below describes the expected motor disturbances associated with lesions to certain areas of the brain:



*Cerebral palsy signs, symptoms, and associated conditions are affected by the location of the brain lesion. This image shows how common each type is, the motor disturbance expected, and some of the associated problems that may affect our care in the prehospital setting.*

**Diagnosis.** The child is usually diagnosed with cerebral palsy when certain developmental milestones are not met as an infant, such as crawling and walking. However, other developmental problems can cause these delays as well, not just cerebral palsy.

The morbidity and mortality of cerebral palsy is dependent on the severity of this condition, the degree of motor loss/paralysis, and the associated medical complications such as respiratory and gastrointestinal problems. Some with cerebral palsy may only have monoplegia (*just one limb affected, usually an arm*).

They usually only experience mild impairments with their activities of daily living. Others may experience spasticity, involuntary movements, and/or paralysis of one or both arms, legs, and even their neck.



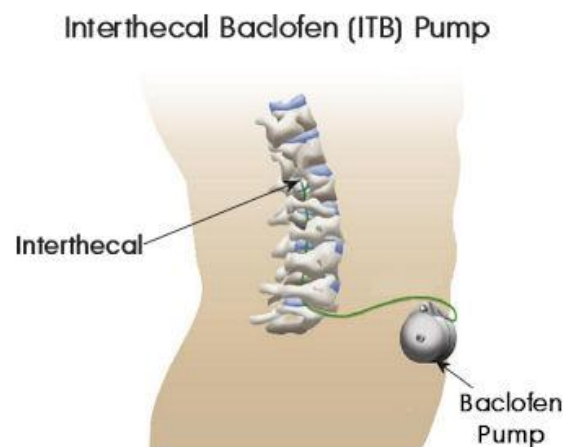
**Improving quality of life.** The patient with cerebral palsy may need a few special devices to improve their motor function, ambulation, decrease pain, and enhance their overall quality of life. We may see or be told about these when caring for these patients in the prehospital setting. Some patients may have undergone surgery (*selective dorsal rhizotomy*) or make regular visits for therapy and injections. Two of the more common devices we may see in the prehospital setting:

Intrathecal baclofen pump. An implanted baclofen pump delivers a metered dose of baclofen to treat spasticity and/or dystonia associated with cerebral palsy. Baclofen is a GABA<sub>B</sub>-receptor agonist that inhibits the release of excitatory neurotransmitters at the level of the spinal cord. As a comparison, the GABA-agonists we're familiar with include benzodiazepines used to control seizures and sedate, such as midazolam (*Versed*) and lorazepam (*Ativan*).

The baclofen pump reduces spasticity of the lower extremities and trunk, but may also benefit the upper extremities and improve speech. The pump is implanted in the anterior abdominal wall and connects to a catheter inserted in the subarachnoid space overlying the conus of the spinal cord. The implanted baclofen pump allows for more local presynaptic inhibition of I-a sensory afferents (*sensory nerves*) and reduces muscle spasticity.

It is filled in the physician's office once a month or on an as-needed basis. The baclofen pump can also be scanned at the office with a portable, handheld reader to adjust dose, measure the amount of medication remaining in the reservoir, and retrieve any error codes.

Braces, splints, and other external supports. Orthotic treatment consists of a series of inserts and braces fitted to address a child's specific needs. These devices not only provide external limb support but can also help to relieve localized pain with padding and improve mobility.

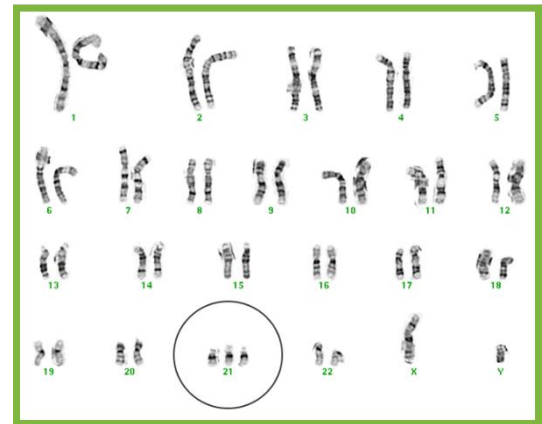


## Down syndrome

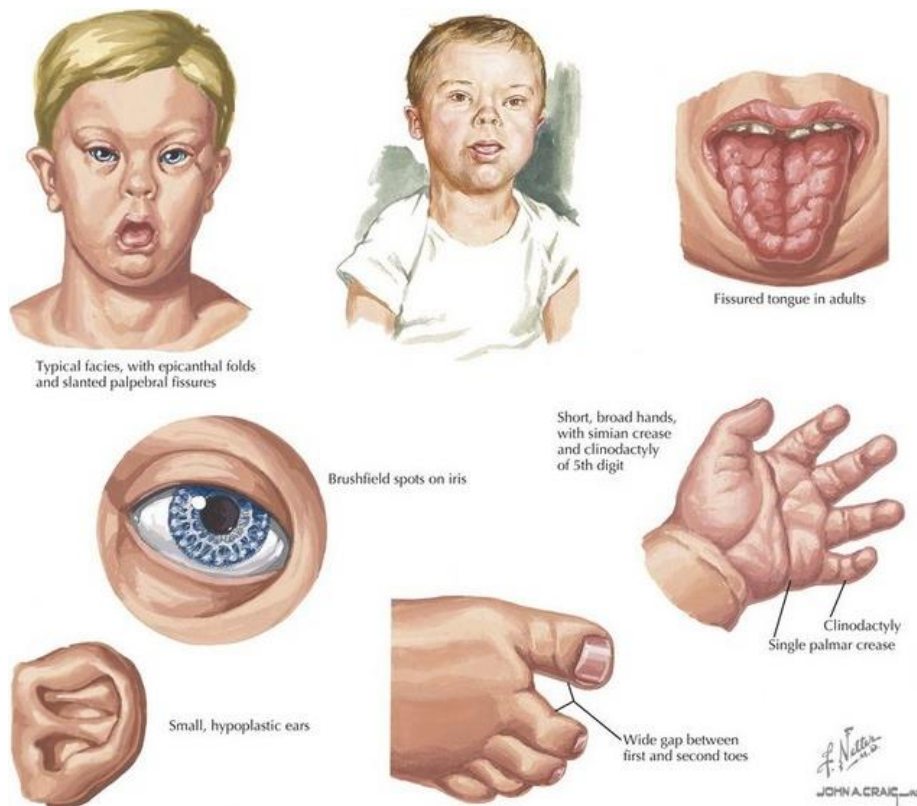
**Trisomy 21 (Down syndrome)** is a common congenital disorder affecting many body systems. It was first described in 1887 by British physician Dr. John Langdon Down. However, the cause wasn't identified until 1959.

During normal conception, a baby inherits genetic information from both parents equally, with 23 chromosomes from the mother and 23 from the father (*totaling 46 chromosomes*). In most cases of Down syndrome, the child receives an extra chromosome 21, and it is this extra material that causes the physical features and developmental delays associated with the syndrome.

This *overexpression* of chromosome 21 alters fetal development at all stages and contributes to the known characteristics of Down syndrome: Intellectual disability, characteristic facial features and hand/foot anomalies, visual/hearing/speech deficits, Alzheimer disease, diabetes, leukemia, depressed immune response, and congenital heart defects.<sup>12,13</sup>



*Image: The chromosome map of a person with Down syndrome, showing three chromosomes at chromosome 21 instead of the normal pair.*



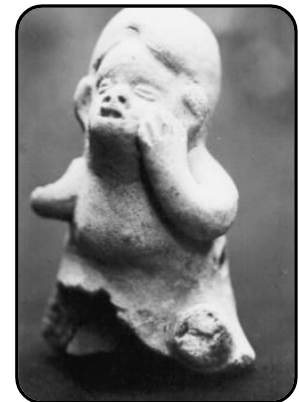
*Image: Physical features typically associated with Down syndrome.*

People with Down syndrome have recognizable physical features, as depicted in the illustration on the previous page. Some of these alterations may affect their ability to care for themselves due to mobility issues, while other features, such as a large tongue within a small oral cavity, can make them more susceptible to serious conditions such as an airway obstruction.

**Epidemiology.** The frequency of Down syndrome in the US is about 1 case in every 800 live births.<sup>14</sup>

Down syndrome may have been documented in cultural art dating back hundreds of years, so is not a new condition brought on by factors such as industrial-era environmental exposure or medication use.

For example, the *Tumaco-La Tolita* people once inhabited the borders of present-day Colombia and Ecuador. Although long extinct, they left behind a large collection of pottery sculptures that depicted their life for 1000 years (as early as 600 BC).<sup>15</sup> The pottery sculpture to the right strongly suggests Down syndrome with the eyes, facial features, and even the child's pose representing the phenotype expected with trisomy21.<sup>15</sup>

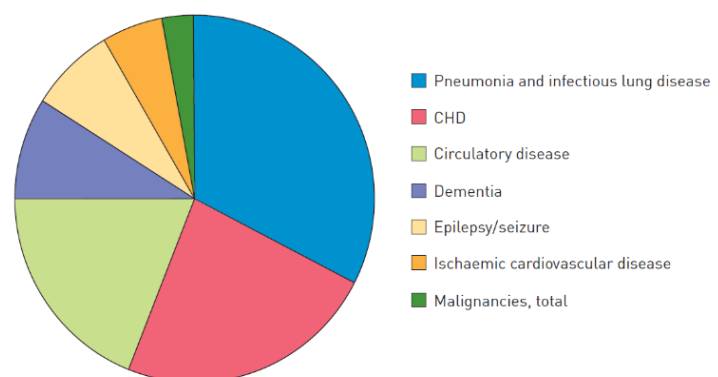


*Image: Pottery from centuries ago from the Tumaco-La Tolita people that depicts the physical features of Down syndrome.*

While there's still little information about the cause of Down syndrome, the odds lean strongly towards maternal age. The incidence estimated at different female age groups:<sup>16</sup>

- 15 to 29 years - 1 case in 1500 live births
- 30 to 34 years - 1 case in 800 live births
- 35 to 39 years - 1 case in 270 live births
- 40 to 44 years - 1 case in 100 live births
- Older than 45 years - 1 case in every 50 live births

In the past, individuals with Down syndrome rarely survived into adulthood. A depressed immune system, high rate of cardiac defects, limited intellect, and decreased mobility kept longevity rates low. But now, the overall outlook for individuals with Down syndrome has dramatically improved with advancements in mobility, therapy, and medical treatment. Many adult patients are healthier, are employed, and have integrated well into society, with their life expectancy improving from just 25 years old in 1983 to 60 years or older today.



*Image: Causes of death for those with Down syndrome. CHD = Congenital Heart Defect (Colvin 2017)*



**Complications.** A person with Down syndrome may have one or more health concerns that can affect prehospital management. The most common ones are described below.

**Congenital heart conditions.** Congenital heart defects are common and the major cause of morbidity and early mortality in those with Down syndrome. About 45 to 50% of babies diagnosed with trisomy 21 have congenital heart defects.<sup>17</sup> Early screening and surgical intervention can greatly increase the quality of life and overall life span in these individuals. The most common heart defects in Down syndrome include atrioventricular septal defects, ventricular septal defects, secundum atrial septal defects, and patent *ductus arteriosus*.

**Immune response.** There's an increased risk for death from infectious disease overwhelming an impaired immune response. Those with Down syndrome usually have mild to moderate T and B cell lymphopenia, marked decrease of naive lymphocytes, impaired mitogen-induced T cell proliferation, reduced specific antibody responses to immunizations, and defects of neutrophil chemotaxis.<sup>18</sup> In other words, their entire immune effectiveness, including responsiveness to vaccination, may be reduced due to the effects of chromosome 21 overexpression on the genetic code of immune system cells. This is still an area of debate though.

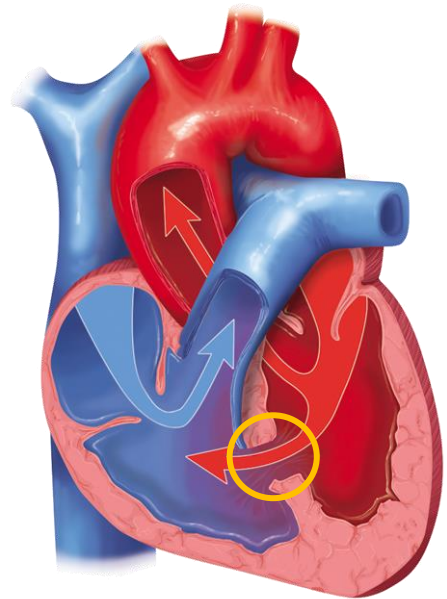


Image: An atrioventricular septal defect

**Airway.** The airway can be complicated as well. Individuals with Down syndrome usually have a large tongue that sits within a small oral cavity. In many cases, it appears that the person's tongue is protruding constantly, but this is just the result of anatomy accommodation. Enlarged tonsils and adenoids, lingual tonsils, choanal stenosis (narrowing of the passageway from the back of one side of the nose to the throat), or glossoptosis (displacement of the tongue toward the pharynx) can obstruct the upper airway. Respiratory infections may be the leading cause of hospitalization for Down Syndrome patients who also have a congenital heart condition.<sup>19</sup>

Airway obstruction can cause *serous otitis media* (ear infection), alveolar hypoventilation, arterial hypoxemia, cerebral hypoxia, and pulmonary arterial hypertension with resulting *cor pulmonale* and heart failure.

In the prehospital setting, patients with Down syndrome are one of the most difficult to intubate and ventilate due to the abnormal anatomy. They have a smaller tracheal diameter, so may require a smaller endotracheal tube (*two sizes down to be expected*) to avoid airway trauma.<sup>20</sup> Positioning is extremely important, especially since patients



Image: Ear-to-sternal-notch alignment makes any intubation easier, but particularly for Down Syndrome patients. Image source: Orange County EMS (Florida).

with Down syndrome may also be obese secondary to hypothyroidism. The *ear-to-sternal-notch* alignment should be a priority while ventilating and before intubation. In addition, people with Down syndrome may also have excessive mobility of the C1 and C2 articulation. Do not hyperextend the head/neck region when positioning the patient or during intubation.

**Dementia.** The aging process appears accelerated in patients with Down syndrome. Many patients develop progressive Alzheimer-like dementia by age 40 years, and 75% of patients have signs and symptoms of Alzheimer disease.

**Spinal cord risks.** Particularly for traumatic injuries, a delay in recognizing atlantoaxial and atlanto-occipital instability may result in irreversible spinal-cord damage. There may be extra “play” (*mobility*) of the C1 and C2 articulation. Extra caution and care must be taken for those patients with suspected head, neck, or spine trauma, or with a mechanism that suggests a strong potential for injury.

**And all the others.** Diabetes, hypothyroidism, bowel obstructions, and seizures need to be considered. A detailed history and blood glucose measurement will help with your patient management.

**Pain management.** One of the most misunderstood concepts centers around the ability of a patient with Down syndrome to feel physical pain. In the past, it was assumed that there was more tolerance to pain in those with intellectual disabilities or Down syndrome based on the observation that self-injurious behaviors were common and pain was not verbally reported by the patient.<sup>21</sup>

However, recent evidence suggests that patients with Down syndrome are at least as sensitive to pain as unaffected people, or may even have a heightened sensitivity to it.<sup>21</sup> Since it’s difficult for many with Down syndrome to clearly verbalize the pain they are feeling, ask their caregiver about the patient’s normal baseline and use visual clues (for example: facial strain, FACES or FLACC numeric pain scale, etc.) to help guide treatment decisions.



# Intellectual Disability

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The term “intellectual disability” now replaces the former reference to cognitive underdevelopment (mental retardation) and even its scope is better defined.

Intellectual disability is defined by an IQ score under 70 and having two or more deficits that affect adaptive functioning (daily living and functional behaviors).<sup>22</sup> Intellectual disability occurs while the brain is still developing, so must be detected when the person is under 18 years old. Causes may include complications while *in-utero*, shortly after birth, or during childhood. For example: The child acquires meningitis, which adversely affects the developing brain or environmental exposure to lead or mercury.



In contrast, intellectual disability is not diagnosed in those who previously had normal intellect and functioning as adults but then declined as they grew older due to Alzheimer’s disease, stroke, or other age-related conditions.

“Mental retardation” was a term that only focused on the intelligence factor. Intellectual disability not only includes the intellect component, but also considers functional skills, such as independent self-care or performing expected work. For example, a person may be able to care for himself (cook, shower, manage money, etc.) and also perform skills related to his employment, such as keeping a machine shop clean. If his IQ test score was 60 but he’s otherwise able to perform everyday tasks, he is not considered as having “intellectual disability”. It misses part of the definition where he would have to possess two or more deficits that affect adaptive functioning. This is not the case in the above example.

Intellectual disability is subdivided into two groups:

- **Syndromic intellectual disability:** The intellectual deficits are associated with other medical conditions (syndromes), such as Down syndrome and Fragile X syndrome. There’s an obvious clinical feature or co-morbidity in this group, such as hand contractures.
- **Non-syndromic intellectual disability:** The intellectual deficits appear without any other abnormalities. They appear “normal”, but the IQ remains below 70 and they have two or more deficits present that affect daily living.

The term “developmental disability” encompasses intellectual disability and includes physical disabilities.<sup>23</sup> This can be found in people with Down syndrome, some cases of cerebral palsy, and other conditions.

**Epidemiology.** The frequency of intellectual disability ranges from 1 to 3% of the US population, with most expressed in a mild form. Severe intellectual disability occurs in approximately 6 per 1,000 people.<sup>22</sup> Many live to become adults, but the life expectancy is shorter. Intellectual disability in itself is not necessarily associated with an increased premature death rate. However, those with severe to profound intellectual disability may experience a decreased life expectancy due to complicating neurologic disorders, such as epilepsy.

## Communicating with the Special Needs Patient

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Those with intellectual disability, Down syndrome, or cerebral palsy all pose unique challenges to EMS. We work in a world where everything seems to be, “hurry up and go”. But in the case of the special needs patient, the opposite is important and we need to slow down, be patient, and listen to both the person and his or her caregiver. The “*Well, you called 9-1-1... there’s no time for that!*” attitude does not work for these patients, is unprofessional, and will understandably cause you more grief with both the patient and caregiver. Some tips to help better interact with the special needs patient:<sup>24</sup>

<b>Introducing Yourself &amp; The Care Environment</b>	<p><b>If possible, try to interact with as few distractions as possible.</b> For example, barking dogs or crowds can increase anxiety and make it more difficult to communicate with your patient and caregiver. Quiet and calm is better.</p> <p><b>Introduce yourself as you normally would with any other patient.</b> Refer to the patient professionally, such as “Mr. Smith” or a name the caregiver suggests. Those with special needs deserve the same respect as any other patient.</p>
<b>Involve the Caregiver</b>	<p><b>Difficulty expressing needs.</b> Some people with severe disabilities may be unable to offer an accurate picture of their feelings and symptoms because of limitations in interpreting internal cues. For example, they may have a difficult time knowing if they need to urinate and may be more prone to “accidents”, especially if stressed.</p> <p><b>Involve caregivers who know the patient well</b> may help you to better understand what is normal and abnormal for the patient. However, as much as possible, continue to focus your communication efforts on the patient.</p> <p><b>Speak directly to the patient whenever possible,</b> not just the caregiver.</p>

<b>Verbal Communication</b>	<p><b>Allow additional time to exchange information.</b> Short sentences are preferred to long, drawn-out questions. Ask one question at a time.</p> <p><b>Some people may delay their response</b> to your questions while they're processing the information, so much so that answers may seem to "come out of nowhere."</p> <p><b>Do not speak to the adult patient as a child or with "baby talk".</b> Use a normal, clear, calm tone of voice intended for any other adult.</p> <p><b>Use concrete terms.</b> For example, instead of asking, "How do you feel?", ask the patient, "Does your arm hurt" or "Do you feel sick to your stomach"?</p> <p><b>The concept of time may be difficult.</b> Instead of asking for a clock time (<i>such as 7 am</i>), consider asking if the pain began near breakfast-time, after a nap, etc.</p>
<b>Improving Trust</b>	<p>If the patient has a <b>special toy or device</b> they feel more comfortable with and it doesn't impede your care, allow him or her to keep it with them.</p> <p><b>Do not "sneak up" with an injection, lie, or hide your intent.</b></p>

## Information more specific to UMC EMS:

<b>Service Animals</b>	<p>At UMC EMS, a <b>service animal may accompany the patient to the hospital as long as it does not pose a safety threat to the crew</b> (<i>growling, etc.</i>) or is "out of control and the handler does not take effective control or the dog is not housebroken" (UMC Policy SPP#PC-36.3). You do <u>not</u> ask for documentation or proof of the animal's occupation, but you may ask if the animal is required because of a disability and what work the animal has been trained to perform, if this is not obvious. You cannot ask for a demonstration of the animal performing the work or task.</p> <p><b>Out of professional courtesy, advise the hospital about the service animal in your radio report so they can make accommodations.</b></p> <p>The animal travels with the patient as long as it's safe to do so. <b>Service animals should not be fed or petted by anyone except the patient</b>, unless the patient gives permission to do so first.</p>
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<p><b>Consent</b></p>	<p><b>The patient should have a voice in his or her medical care and decisions</b>, unless certain circumstances suggest this will cause harm and the patient is unable to comprehend this risk. The caregiver can be invaluable in helping you communicate with the patient.</p> <p>Important question to ask: <b>Can the patient make his or her own medical decisions?</b></p> <p>Remember that the patient who can make decisions about their healthcare <b>can refuse any or all treatments</b>, and you must respect their decision as with any other patient.</p> <p>However, you need to make sure the patient has <i>decisional capability</i> for a refusal. Does the patient understand what might be causing the pain or discomfort? Does the patient understand the risks of refusal and delayed evaluation by a physician? Can the patient tell you signs and symptoms that suggest the condition is worsening? What are the plans after you leave, and who will remain with the patient? Ask the patient to explain what they understand in their own words.</p> <p>If the patient does not provide acceptable answers to these questions, it would not be safe to allow them to refuse. As with any other patient, you cannot just hand them your computer and tell them to “sign here and I’ll go away”. As with all of our patients, the decision to refuse must be informed and with a full understanding of the risks inherent with refusal. If no one on scene can convince the patient to go to the hospital, contact medical control for help.</p>
<p><b>Caregivers</b></p>	<p>In most cases, <b>the caregiver should accompany the patient to the hospital</b> if the patient prefers this arrangement, the caregiver is not a threat to the crew or their safety, and he or she will wear a seatbelt during transport.</p> <p><b>Exceptions to a rider include code 3 transport to the hospital (<i>lights and sirens</i>)</b> due to safety concerns during expedient travel.</p>

As with any patient, always assess the airway, breathing, and circulatory status and make appropriate treatment decisions. Learn what the normal baseline vital signs are for the patient, if he or she is acting appropriately, home medications, and be sure to bring the patient’s “Go Bag” (*if one exists*) that contains supplies needed to manage the patient’s daily care.

*Please let a member of the training staff know of any questions. Thank you!*

## References

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1. Farrag K, Shastri YM, Beilenhoff U, *et al.* Percutaneous endoscopic gastrostomy (PEG): a practical approach for long term management. *BMJ*. 2019;364:k5311. Published 2019 Jan 22. doi:10.1136/bmj.k5311
2. Blumenstein I, Shastri YM, Stein J. Gastroenteric tube feeding: techniques, problems and solutions. *World J Gastroenterol*. 2014 Jul 14;20(26):8505-8524. doi: 10.3748/wjg.v20.i26.8505.
3. Willwerth BM. Percutaneous endoscopic gastrostomy or skin-level gastrostomy tube replacement. *Pediatr Emerg Care*. 2001 Feb;17(1):55-58.
4. Gogakos A, Barbetakis N, Lazaridis G, *et al.* Heimlich valve and pneumothorax. *Ann Transl Med*. 2015;3(4):54. doi:10.3978/j.issn.2305-5839.2015.03.25
5. Mutch LW, Alberman E, Hagberg B, *et al.* Cerebral palsy epidemiology: where are we now and where are we going? *Dev Med Child Neurol* 1992;34:547-555.
6. Rosenbaum P, Paneth N, Leviton A, *et al.* A report: the definition and classification of cerebral palsy. April 2006 [*published correction appears in Dev Med Child Neurol*. 2007 Jun;49(6):480]. *Dev Med Child Neurol Suppl*. 2007;109:8-14.
7. Data and statistics for cerebral palsy. Centers for Disease Control and Prevention. *Web page*: <https://www.cdc.gov/ncbddd/cp/data.html>. Accessed on March 19, 2021.
8. Quick Facts: Lubbock city, Texas. United States Census Bureau. *Web page*: <https://www.census.gov/quickfacts/fact/table/lubbockcitytexas/PST045219>. Accessed on March 20, 2021.
9. Facts about Cerebral Palsy. Centers for Disease Control and Prevention. *Web page*: <https://www.cdc.gov/ncbddd/cp/facts.html>. Accessed March 20, 2021.
10. Odding E, Roebroek ME, Stam HJ. The epidemiology of cerebral palsy: incidence, impairments and risk factors. *Disabil Rehabil*. 2006 Feb 28. 28(4):183-91.
11. Russman BS and Ashwal S. Evaluation of the child with cerebral palsy. *Semin Pediatr Neurol*. 2004 Mar. 11(1):47-57.
12. Kazemi M, Salehi M, Kheirollahi M. Down syndrome: Current status, challenges and future perspectives. *Int J Mol Cell Med*. 2016 Summer;5(3):125-133.
13. Malt EA, Dahl RC, Haugsand TM, *et al.* Health and disease in adults with Down syndrome. *Tidsskr Nor Laegeforen*. 2013 Feb 5;133(3):290-294. doi: 10.4045/tidsskr.12.0390.

14. Canfield MA, Honein MA, Yuskiv N, *et al.* National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999-2001. *Birth Defects Res A Clin Mol Teratol.* 2006 Nov. 76(11):747-756.
15. Bernal JE and Briceno I. Genetic and other diseases in the pottery of Tumaco-La Tolita culture in Colombia–Ecuador. *Clin Genet* 2006; 70: 188–191. doi: 10.1111/j.1399-0004.2006.00670.x
16. Mundakel GT, Lal P. Down syndrome. Medscape. *Available at:* <https://emedicine.medscape.com/article/943216-overview#a5>. Accessed: March 19, 2021.
17. Colvin KL and Yeager ME. What people with Down syndrome can teach us about cardiopulmonary disease. *Eur Respir Rev.* 2017 Feb 21;26(143). pii: 160098. doi: 10.1183/16000617.0098-2016.
18. Ram G and Chinen J. Infections and immunodeficiency in Down syndrome. *Clin Exp Immunol.* 2011 Apr;164(1):9-16. doi:10.1111/j.1365-2249.2011.04335.x
19. So SA, Urbano RC, Hodapp RM. Hospitalizations of infants and young children with Down syndrome: evidence from inpatient person-records from a statewide administrative database. *J Intellect Disabil Res.* 2007 Dec;51(Pt 12):1030-1038.
20. Shott SR. Down syndrome: analysis of airway size and a guide for appropriate intubation. *Laryngoscope.* 2000 Apr;110(4):585-592.
21. McGuire BE and Defrin R. Pain perception in people with Down syndrome: a synthesis of clinical and experimental research. *Front Behav Neurosci.* 2015; 9: 194. doi: 10.3389/fnbeh.2015.00194
22. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th Edition. Washington, DC: APA Press; 2013.
23. Intellectual and Developmental Disabilities. National Institute of Health. *Web page:* <https://www.nichd.nih.gov/health/topics/factsheets/idds>. Accessed March 20, 2021.
24. Health Care for Adults with Intellectual and Developmental Disabilities: Communicating Effectively. Vanderbilt Kennedy Center, Vanderbilt University (TN). *Web page:* <https://iddtoolkit.vkcsites.org/general-issues/communicating-effectively/>. Accessed March 20, 2021.

## Image Credit

Farrag K, Shastri YM, Beilenhoff U, Aksan A, Stein J. Percutaneous endoscopic gastrostomy (PEG): a practical approach for long term management. *BMJ*. 2019;364:k5311. Published 2019 Jan 22. doi:10.1136/bmj.k5311

Hemodialysis Access. Gaytri Gandotra (Manek), MD. Web page: <https://www.thekidneydr.com/learning-center/dialysis/hemodialysis-access/>. Accessed March 17, 2021.

Gogakos A, Barbetakis N, Lazaridis G, et al. Heimlich valve and pneumothorax. *Ann Transl Med*. 2015;3(4):54. doi:10.3978/j.issn.2305-5839.2015.03.25

Colvin KL and Yeager ME. What people with Down syndrome can teach us about cardiopulmonary disease. *Eur Respir Rev*. 2017 Feb 21;26(143). pii: 160098. doi: 10.1183/16000617.0098-2016.