

# Children With Special Health Care Needs

## Provider Manual



GEORGIA  
DEPARTMENT OF  
HUMAN RESOURCES

*Division of Public Health*

## **Special Needs and Technology Assisted Children**

### **Introduction**

Thousands of children and adolescents each year are rushed to emergency departments following serious injury or illness. The National Center for Health Statistics reports approximately 20,000 of these children lose their lives and another 50,000 are permanently disabled.

The needs of all children including those with special health care needs must be considered when preparing for and responding to severe illness or injury. Children with special health care needs (CSHCN) have medical conditions that could place them at greater risk during a medical emergency. In addition, some children that acquire disabilities as a result of their injury or illness may need rehabilitation and other services that require special coordination of resources. It is important that everyone involved including parents, teachers, bystanders, paramedics, nurses, doctors, and specialists are aware of a child's special needs, both in preparing for and surviving a medical emergency. Families of children with special needs should participate in the development of a written emergency care plan which is easily accessible and includes provisions for any special training for emergency medical personnel, family members and others who may be called on to provide emergency care for the child.

This lecture and discussion program is designed to present health professionals with information, which will enhance their knowledge of the definition of special needs, and technology-assisted children and management of an emergency based on the individual needs of the child.

Children with special health care needs may have physical disabilities that make them particularly susceptible to medical problems involving the airway, breathing, and circulation. Since these children often find it difficult to tolerate respiratory distress or shock, out-of-hospital providers should consider these medical problems urgent. Technology-assisted children may also experience medical emergencies if the medical devices on which they depend fail to function properly.

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## **Objectives:**

- ❖ Discuss the special considerations for assessing vital signs in children with special health care needs.
- ❖ Discuss the unique assessment priorities of the initial, focused, and detailed examinations for children with special health care needs.
- ❖ Explain the importance of getting patient information and other assistance from parents or home care providers.
- ❖ Discuss the management of a child with a tracheostomy tube, including types of tubes, obstruction management, suctioning techniques and the correct procedure for changing a tracheostomy tube.
- ❖ Discuss the management of a child who is ventilator dependent, including special transport considerations, breathing assessment, and types of ventilators.
- ❖ Explain the purpose of continuous positive airway pressure (CPAP).
- ❖ Discuss the medical purpose, types, and possible complications of central intravenous catheters, feeding tubes, and cerebral spinal fluid (CSF) shunts.
- ❖ Discuss the management of the child with Congenital Heart Disease, including the special circumstances of fluid overload and pulmonary edema.
- ❖ Describe the special considerations for transporting children with mobility problems.
- ❖ Describe special assessment considerations for children with paralysis.
- ❖ Discuss special assessment considerations for children with chronic illness.
- ❖ Discuss the differences between Mental Retardation and Developmental Delay.
- ❖ Discuss the necessity of interacting with the Developmentally Delayed child and the importance of involving them in their assessment and health care.

## **Assessment and Management**

### **Introduction to Assessment**

The term *children with special health care needs* refers to children with any type of disability, including physical limitations, mental limitations, or chronic illness. This term could be applied to a frail child who suffers from asthma; a child with delayed development, or a premature baby. The term *technology-assisted children*, refers to children with special health care needs who depend on medical devices to support bodily functions. This term could be applied to a child with a tracheostomy, mechanical ventilator, or pacemaker.

There are several reasons why health professionals may be seeing more children with special health care needs than in the past:

- ❖ Advances in intensive care management have improved survival rates for children with traumatic brain injuries, premature infants with lung disease, children with chronic illness, and children with birth defects.
- ❖ Advances in medical treatment and surgical interventions have made it possible for children with feeding problems, serious infections, and chronic illness to receive necessary liquid nutrients and medications intravenously at home.
- ❖ Advances in medical technology have allowed children with life-threatening airway and breathing problems to live at home using specialized monitoring and respiratory equipment.
- ❖ Cost-cutting measures have altered medical practice, so those children with special health care needs are transferred from hospital care to home care as soon as they are stable.

### **Initial Assessment Considerations**

Assessment priorities for children with special health care needs are generally the same as for other children. However, these children may have unusual baseline vital signs, and their physical and mental capabilities may not be the same as those for other children of a similar age. These factors can affect the way you approach the initial assessment. They can also change evaluation of assessment findings.

For example, a five-year-old child normally has a heart rate between seventy and 110 with a respiratory rate between eighteen and twenty-five. However, a five-year-old child with a heart problem or tracheostomy may normally have a heart rate of 150 and a respiratory rate of forty. The higher rates would be acceptable for this child. In technology-assisted children, vital signs may be controlled by the child's medical device. For example, equipment settings would determine the heart rate for a child with a pacemaker.

We can more accurately determine the seriousness of the child's condition if we base our assessment of the child's own typical vital signs and physical or mental abilities. Therefore, begin by asking the parents or home care providers about the child's on-going health problems, normal assessment findings, and medical devices currently in use. Also, find out whether the child has any limitations affecting growth, neurological development, physical function, or level of education.

If no other source of information is available, you should see whether the child has a clinical information folder listing normal vital signs and other routine assessment findings, including recent hospitalizations and the reason for the hospitalization. If you are unable to obtain historical information, you should base the assessment on normal vital signs for the child's age.

Following is a brief summary of some specific considerations that may affect your approach to assessment and management:

❖ **Airway Considerations**

Many children with special health care needs are susceptible to airway obstruction and the complications that can arise from it. This is particularly true of brain-damaged children, who may have difficulty swallowing saliva, as well as children with tracheostomies, children on home ventilators, and children with continuous positive airway pressure (CPAP) devices.

❖ **Breathing Considerations**

Children with congenital heart disease or chronic illness are often unable to compensate effectively for breathing problems. As a result, their condition may worsen more rapidly than you would normally expect.

❖ **Circulatory Considerations**

Signs of early shock may be hard to detect in some technology-assisted children because their normal heart rate is faster than usual. Careful circulatory assessment is particularly important in children with pacemakers and congenital heart disease. Children who have pacemakers or who suffer from chronic illness are often unable to tolerate shock, and their condition may worsen more rapidly.

❖ **Mental Status Considerations**

Children with special health care needs may have an altered mental status as their usual baseline condition. This is often true of children with mental retardation or developmental delay. Parents or home care providers are best able to judge whether the child's behavior and level of functioning are different from usual. You must ask for information about the child's baseline mental status in order to assess the child accurately.

## **Assessment: Critical, Unstable, Potentially Unstable, Stable (CUPS)**

At minimum, you should consider any child with special health care needs potentially unstable.

A child with special health care needs who has any of the following conditions should be considered unstable:

- ❖ Partially or totally obstructed tracheostomy
- ❖ Respiratory difficulties in ventilator-dependent children
- ❖ Slow heart rate, irregular pulses, or signs of early shock in children with pacemakers
- ❖ Fever, nausea, vomiting, headache, or a change in normal mental status in children with Cerebral Spinal Fluid (CSF) shunts
- ❖ Signs of worsening illness in any child who has a chronic health problem and has taken appropriate home therapy for the problem

A child with special health care needs who is unable to maintain an open airway, requires assisted ventilation, has no pulse, or has a potentially unstable mental status has a CUPS status of critical. It should be noted that since ventilator-dependent children always require assisted ventilation, the critical status applies only if one or more of the other signs is also present.

The accompanying table summarizes assessment findings that help determine the CUPS status. The CUPS assessment will be more accurate if you are able to base the initial assessment on the child's typical baseline vital signs.

<b>CUPS Assessment of Children with Special Health Care Needs</b>		
<b>Category</b>	<b>Assessment</b>	<b>Actions</b>
<b><i>Critical</i></b>	Absent airway, breathing, or circulation; AVPU= P or U	Perform initial interventions and transport simultaneously; advanced life support should be available
<b><i>Unstable</i></b>	Compromised airway, breathing, or circulation and AVPU=V or P; OR normal airway, breathing, and circulation, AVPU=A, and additional risk factors are present	Perform rapid initial assessment and interventions; advanced life support should be available; transport promptly to definitive care
<b><i>Potentially Unstable</i></b>	Normal airway, breathing, and circulation; AVPU=A	Perform initial assessment and interventions; transport promptly; begin focused history and physical exam during transport
<b><i>Stable</i></b>	<b>Children with special health care needs should not be considered stable.</b>	

Based on CUPS Assessment Table ©1997 N.D. Sanddal, et al. Critical Trauma Care by the Basic EMT, 4<sup>th</sup> ed.

## Focused History and Detailed Physical Examination

Children with special health care needs may have a variety of medical problems and physical findings that affect out-of-hospital and emergency department care. In many cases, the parents or home care provider will alert you to these special considerations during the course of the initial assessment and interventions. If the child's condition is non-urgent and the child is in the out-of-hospital environment, you can continue the focused history and physical examination until emergency services arrive or during transport to the emergency department. Some of the findings that may be associated with specific medical conditions or devices are discussed in the following sections.



## Special Technology

### Tracheostomies

Located at the front of the neck, a tracheostomy (also called a stoma) is a surgical opening into the windpipe through which an artificial airway or tracheostomy tube (also called a trach tube) can be passed. The child then breathes, either partially or completely, through this tube. A child may have a tracheostomy to:

- ❖ bypass an upper airway obstruction caused by birth defects, surgery, or trauma.
- ❖ allow long-term mechanical respiratory support to offset breathing difficulties caused by certain diseases affecting the central nervous system, lungs, or muscles.
- ❖ aid in the removal of secretions.

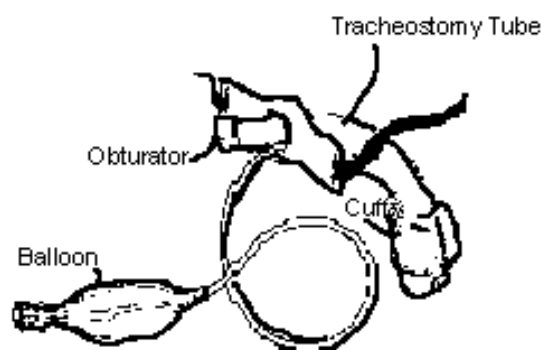
### Tracheostomies Tubes

Tracheostomy tubes come in several sizes and types. Sizes are marked on the sterile packaging and on the wings of each tracheostomy tube and typically range from 000 (for newborns) to 10 (for older adolescents). Sizing may vary according to the type of tube and the manufacturer. If you must replace a tracheostomy tube, you should try to use the same size and type of tube that is already in place.

All tracheostomy tubes have a standard external opening so that they can be attached to a bag-valve device should the patient require assisted ventilation. Infrequently, a tracheostomy tube may need an adapter to fit the bag-valve device.

Some tracheostomy tubes have a cuff on the end, which acts as a seal to eliminate or reduce airflow through the mouth and nose. There are balloon cuffs, which can be inflated and deflated, and form cuffs. Pediatric tracheostomy tubes may have a cuff, depending on the child's size and whether air leakage has been a problem. Cuffs are not necessary on newborn tracheostomy tubes because the infant's narrow trachea forms a natural cuff around the tube. See *Figure 1: Cuffed Tracheostomy Tube Adult*

Figure 1: Cuffed Tracheostomy Tube



Types of tracheostomy tubes include:

- ❖ **Single cannula** - All newborn tracheostomy tubes and most pediatric tubes are of this type. A single cannula tube provides a single passage for airflow and suctioning of secretions. There is nothing to keep the stoma open when this tube is removed for changing, so a new tube should be inserted as quickly as possible. Single cannula tubes are placed using a plastic insert called an obturator, which helps keep the flexible tube from kinking, closes off the opening to the tube during insertion, and provides a blunt tip to help prevent tissue trauma. The obturator must be removed immediately after insertion to avoid obstructing the airway. *See Figure 2: Single Cannula Tracheostomy Tube*
  
- ❖ **Double cannula** - Available in sizes four to eight, these tubes have a removable inner cannula that fits inside an outer cannula or sheath. The inner cannula provides a passageway for airflow and removal of secretions, and must be in place for manual or mechanical ventilation. The outer tube is inserted into the trachea and keeps the stoma open when the inner cannula is removed for cleaning. *See Figure 3: Double Cannula Tracheostomy Tube*
  
- ❖ **Fenestrated** - This type of tracheostomy tube teaches the child to breathe naturally and allows the child to talk. The fenestrated tracheostomy tube has a decannulation plug attached to the outer cannula. The decannulation plug blocks airflow through the stoma, directing it instead through a small hole in the tube, past the vocal cords and out to the nose and mouth. If the child is unable to breathe through the mouth and nose due to airway obstruction, the decannulation plug must be removed so that the child can breathe through the stoma. *See Figure 4: Fenestrated Tracheostomy Tube*

Figure 2: Single Cannula Tracheostomy Tube

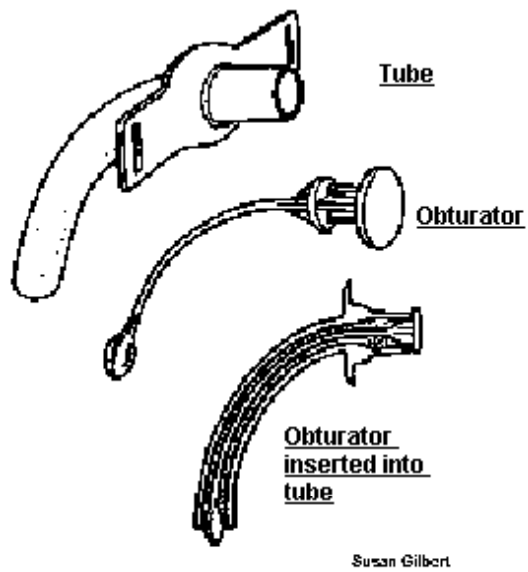


Figure 3: Double Cannula Tracheostomy Tube

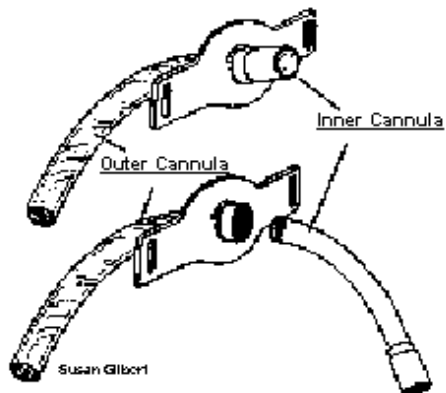
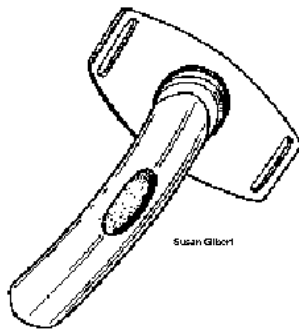


Figure 4: Fenestrated Tracheostomy Tube



### **Tracheostomy Obstruction**

Technology-assisted children who have tracheostomies can suffer significant airway obstruction involving the tracheostomy site of the airway itself. In particular, a child with a tracheostomy may have difficulty clearing secretions, since the surgical opening in the windpipe bypasses the normal upper airway passages. Other common causes of airway obstruction include:

- ❖ improper airway positioning.
- ❖ incorrect insertion of the tracheostomy tube.
- ❖ mechanical problems with the tracheostomy tube.

Emergency care providers should suspect a tracheostomy obstruction if the child has no chest rise during assisted ventilation, or if the child is unable to breathe alone after assisted ventilation.

The following findings may also indicate a tracheostomy obstruction:

- ❖ Signs of respiratory distress or failure (with or without abnormal breath sounds).
- ❖ Only faint breath sounds on both sides of the chest despite significant respiratory effort.
- ❖ Altered mental status.

However, before beginning aggressive airway management actions, you should ask the parents whether these findings are usual or unusual for the child.

## **Overview - Tracheostomy Management Actions**

- ❖ Place a rolled towel under the child's shoulders to maintain the airway. This will allow you to open and assess the airway.
- ❖ Make sure the tube is properly seated and the obturator has been removed or in the case of a fenestrated tube, make sure the decannulation plug is removed.
- ❖ If there is no improvement, inject sterile saline and attempt to suction the tracheostomy tube.
- ❖ If there is no improvement in the child's condition, attempt assisted ventilation through the tracheostomy tube. In ventilator-dependent children, disconnect the tracheostomy tube from the home ventilator and attach it to the bag-valve device.
- ❖ If there is no improvement, attempt to remove and replace the tracheostomy tube.
- ❖ If there is no improvement, or if tracheostomy tube replacement is not possible, attempt to perform bag-valve-mask ventilation directly over the stoma or to the patient's mouth while blocking the stoma.

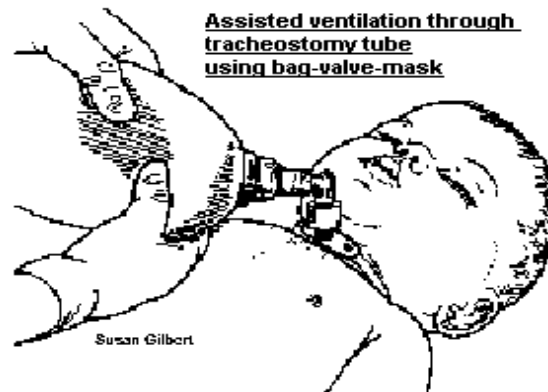
## **Delivering Assisted Ventilation Through a Tracheostomy Tube**

Children who breathe through a tracheostomy tube should receive assisted ventilation through the tube. All tracheostomy tubes have a standard external opening on which you can attach a bag-valve device. If the patient has a double cannula tracheostomy tube, the inner cannula must be in place. Infrequently, a tracheostomy tube may need an adapter to fit the bag-valve device. To provide assisted ventilation:

- ❖ Remove the mask from a bag-valve device
- ❖ Attach the bag-valve device to the tracheostomy tube
- ❖ Follow normal procedures for assisted ventilation with supplemental high-concentration oxygen.

*See Figure 5: Ventilation through Tracheostomy Tube*

Figure 5: Ventilation through Tracheostomy Tube



### Suctioning a Tracheostomy Tube

In the out-of-hospital environment you should ask parents or home care providers to help suction the tracheostomy tube, since they are usually trained in this procedure. Suctioning a tracheostomy tube involves the following steps:

- ❖ Ask parents or home care provider whether they have suctioning apparatus, equipment, and supplies. Use this equipment if available, since it should be appropriate for the child's needs.
- ❖ Use a suction catheter from the patient's supplies, if available. Otherwise, select a suction catheter small enough to pass easily through the tracheostomy tube. For example, a size one tracheostomy tube will accept a French catheter sized from six to eight French. The parents or home care provider may know the correct size catheter for the tube.
- ❖ If using a portable-suctioning machine, set it to 100 mm/Hg or less.
- ❖ Before beginning suctioning, you should allow the child to take a few deep breaths or ventilate the child with high-concentration oxygen. Deliver the oxygen by covering the tracheostomy site with a stoma mask or a pediatric facemask. To give blow-by oxygen, hold the oxygen tubing close to the tracheostomy tube opening. Set the oxygen flow rate at 10 to 15 liters per minute.
- ❖ After giving oxygen, loosen secretions by injecting up to 1 cc of normal saline into the tracheostomy tube using a 3 to 5 cc syringe.
- ❖ Insert the suction catheter approximately two inches into the tube. Never use force when inserting the suction catheter, as this may damage soft tissues of the windpipe.
- ❖ Apply suction for no longer than ten seconds while slowly withdrawing the catheter, rolling it between the fingers. *See Figure 6a-b: Suctioning Tracheostomy Tube*
- ❖ Monitor the child's pulse rate and overall condition throughout suctioning. Stop suctioning immediately if the pulse rate slows or the child appears pale or blue.
- ❖ If suctioning must be repeated, allow the child to take several breaths or ventilate with high-concentration oxygen before beginning another attempt.

Figure 6a: Suctioning Tracheostomy Tube – Insertion of suction catheter to proper depth; suction port remains open

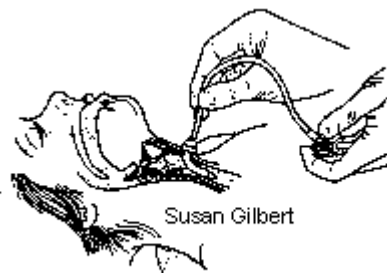


Figure 6b: Suctioning Tracheostomy Tube – Suctioning airway in circular motion as catheter is removed; suction port closed



### **Removing and Replacing a Tracheostomy Tube**

If breathing is still inadequate after assisted ventilation, you may need to remove the tracheostomy tube and replace it. If the tube has been dislodged from the stoma, you will need to inspect the tube and reinsert it, provided the air passage is open or can be cleared with suctioning.

You should check with the parents or home care provider to make sure they agree that the tube requires changing. Also ask them whether there are any special problems or requirements involving their child's tracheostomy. Most parents or home care providers are trained in clearing and replacement procedures, so you should ask them to help with the process in the out-of-hospital environment.

### ***Children with Special Health Care Needs***

If there is any delay in replacing the tracheostomy tube and the patient is not breathing adequately; you may need to provide assisted ventilations before beginning the procedure, following the procedure described in the previous section.

Changing a tracheostomy tube involves the following steps:

- ❖ Ask the parents or home care provider for a replacement tracheostomy tube.
- ❖ If the existing tube has a balloon cuff, deflate it as follows:
  - 1) Connect a syringe to the valve on the pilot balloon. The parents will usually have an appropriate syringe.
  - 2) Draw air out until the balloon collapses. Note that cutting the pilot balloon will not deflate the cuff.
- ❖ Cut the cloth ties that hold the tracheostomy tube in place and remove the tube.
- ❖ Gently insert the new tracheostomy tube, with the curve of the tube pointing downward. ***Never force the tube.*** If the tracheostomy tube cannot be easily inserted, withdraw the tube and begin again. Try a smaller tube if the second attempt is unsuccessful. If the smaller tube fails, try to insert an endotracheal tube while providing high-concentration oxygen through the stoma. If an endotracheal tube is placed, be sure to aim the tip of the tube downward after passing it through the stoma.
- ❖ After the tracheostomy tube has been replaced, assess breathing. Suction the tube if breathing does not appear adequate.

In the case of a double cannula tube, you should remove the inner cannula, clean it, and reinsert it, or remove and replace the inner cannula. If replacing the inner cannula fails to clear the airway, you should remove the outer cannula as well, provide oxygen, and then replace the inner and outer tubes.

Always check for proper placement after replacing a tracheostomy tube:

- ❖ Signs of proper placement include equal chest rise and breath sounds on both sides of the chest.
- ❖ Signs of improper placement include resistance during insertion, bleeding at the insertion site, bleeding through the tube, lack of chest rise, unusual resistance during assisted ventilation, or signs of air in the tissues below the skin, which can be felt as a mild popping sensation.



To avoid improper placement, you can use a suction catheter as a guide:

- ❖ Without applying suction, insert the suction catheter first through the new tracheostomy tube, then through the surgical opening into the windpipe, aiming the tip downward.
- ❖ Slide the tracheostomy tube along the suction catheter and into the opening, and then withdraw the suction catheter from the tracheostomy tube. Do not let go of the suction catheter at any time before removing it from the tracheostomy tube. See *Figure 7a-d: Tracheostomy Tube Placement*
- ❖ After confirming proper placement of the tracheostomy tube, tightly secure new cloth ties.

Figure 7a: Tracheostomy Tube Placement - Insertion of suction catheter



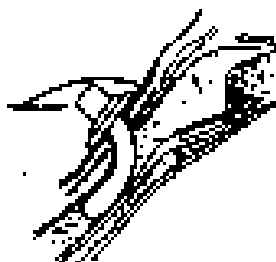
Figure 7b: Tracheostomy Tube Placement - Insertion of suction catheter through stoma in airway



Figure 7c: Tracheostomy Tube Placement - Placement of tracheostomy tube in airway



Figure 7d: Tracheostomy Tube Placement - Tracheostomy tube in airway



### **Delivering Assisted Ventilations Through Stoma or Mouth**

If a tracheostomy tube is obstructed and cannot be cleared, or if you are unable to insert a new tracheostomy or endotracheal tube, the child may need to be ventilated through the stoma. In this case, you should attempt assisted ventilation by placing either a stoma mask or a newborn facemask directly over the stoma. While this is not ideal, it may be the only way to ventilate the child. See *Figure 8a-b: Ventilation Through Stoma*

### **Additional Interventions**

Children with tracheostomies often have asthma and may require treatment with a prescribed oral inhaler after the tracheostomy tube has been cleaned and replaced. Assist parents in this procedure.

Figure 8a: Ventilation Through Stoma - Assisted ventilation through stoma; patient's mouth closed

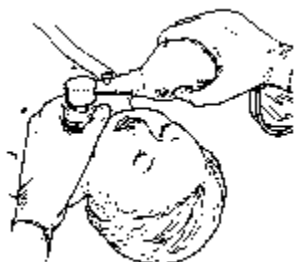


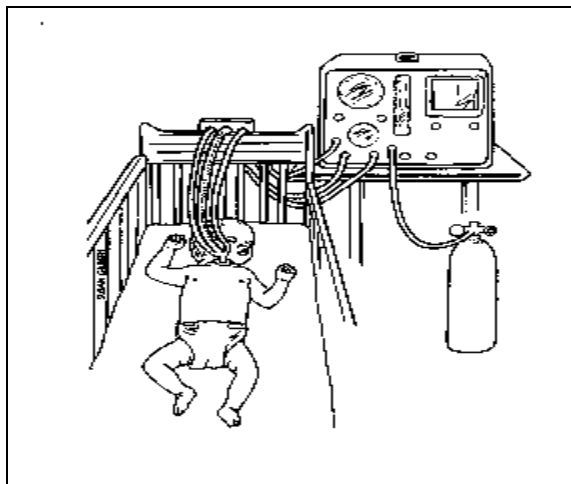
Figure 8b: Ventilation Through Stoma - Assisted ventilation through mouth and nose; stoma covered



## **Home Ventilators**

Children who depend on home ventilators generally have a problem affecting their respiratory drive or respiratory effort; the ventilator helps these children breathe. A child with absent respiratory drive must be supported by the ventilator at all times, while children who have partial absence of respiratory drive or ineffective respiratory effort may only require occasional support during sleep or times of illness. The ventilator is almost always connected through a tracheostomy tube. *See Figure 9: Home Ventilator*

Figure 9: Home Ventilator - Infant with tracheostomy on home ventilator



**Note:** Ventilator tubes should not be elevated as this will allow water to drain into the lungs.

Home ventilators are similar to the models used in hospitals. Most will operate for some time on battery power. Home ventilator settings may include:

- ❖ Breath rate - the number of times per minute the ventilator delivers a mechanical breath.
- ❖ Tidal volume - the volume of air delivered with each breath.
- ❖ FiO<sub>2</sub> - percent of oxygen delivered.
- ❖ Peak End Expiratory Pressure (PEEP) – used to expand or keep the alveoli expanded at the end of expiration. Leaves a small amount of air pressure in the lungs to prevent the air passages from collapsing when the patient breathes out.

There are two types of home ventilators:

- ❖ Pressure-cycled ventilators are set to deliver a given pressure with each breath. The ventilator delivers a tidal volume that corresponds to the pressure setting.
- ❖ Volume ventilators are set to deliver a fixed tidal volume with each breath. The ventilator then delivers the correct pressure to correspond to that tidal volume.

There are two common modes of ventilation:

- ❖ In intermittent mechanical ventilation (IMV), the machine delivers a mechanical breath between the patient's spontaneous respiration to ensure that the patient achieves a certain number of breaths per minute. Some devices have an alternate mode in which the ventilator gives a mechanical breath at the same time that the patient attempts to take a breath.
- ❖ In continuous/conventional mechanical ventilation (CMV), the machine delivers a set number of breaths per minute, whether or not the patient can breathe without assistance.

### **Ventilator Management**

When a ventilator-dependent child develops airway or breathing problems, ask the parents or home care provider to help determine the cause. Possible causes include:

- ❖ Equipment failure involving the ventilator itself
- ❖ Problems with the oxygen supply
- ❖ An obstruction in the ventilator tubing
- ❖ An obstruction in the tracheostomy tube
- ❖ A medical condition

The parents and home care provider are usually familiar with the correct ventilator settings as well as necessary adjustments for respiratory difficulty or illness, and should be able to help with the equipment.

If the child shows signs of respiratory distress or failure and the source of the problem cannot be found and corrected quickly, remove the child from the ventilator and provide assisted ventilation using a bag-valve device.

- ❖ Disconnect the ventilator tubing from the tracheostomy tube.
- ❖ Ask the parents to turn the ventilator off to prevent the alarm from sounding.
- ❖ Attach the bag-valve device to the opening of the tracheostomy tube and begin manual ventilation.
- ❖ Watch and listen for equal chest rise and breath sounds.
- ❖ If chest rise is shallow, adjust the patient's airway positioning and check to see that the bag-valve device is securely connected to the tracheostomy tube. If chest rise does not improve, assess the tracheostomy tube for obstructions as described in the tracheostomy section.

## **Transport Considerations**

Whenever possible, transport a ventilator-dependent child without interrupting the ventilator. This is appropriate as long as the ventilator is functioning properly and the child is not experiencing respiratory problems. The parents should be able to provide information on proper transport procedures.

## **Continuous Positive Airway Pressure (CPAP)**

A technique called *continuous positive airway pressure (CPAP)* helps keep the airway open for children who have recurring problems with partial airway obstruction or weak respiratory effort. These problems may be caused by an anatomical obstruction of the airway or by a disorder affecting the muscles that keep the airway open.

CPAP involves a device that covers the child's mouth and nose, providing continuous airway pressure as the child breathes in and out. Some children wear the device at all times, while others require it only when sleeping, when airway obstruction is most likely. *See Figure 10: CPAP*

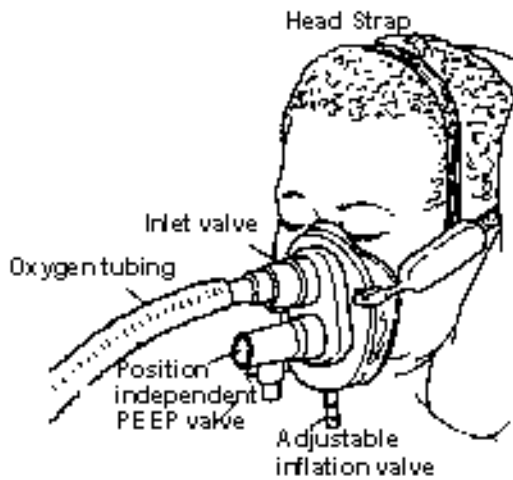
## **Management Considerations**

When children who require a CPAP device experience serious illness or trauma, they usually have a higher than average risk for partial or total airway obstruction.

Emergency care providers should access for respiratory problems using the child's typical baseline vital signs, if known. If the child shows signs of breathing difficulty, ask the parents or home care provider whether the child's discomfort exceeds what is usual for that child. If so, they should prepare the child for transport. Since excessive breathing problems may indicate that the CPAP device is not working properly, try disconnecting the device to see whether the child improves. If the child's condition worsens, it may indicate that the CPAP was not the problem, reconnect the device.

A continual assessment of the child's respiratory status throughout interventions and transport is essential. Provide assisted ventilation using a bag-valve-mask if the child develops breathing problems or if the airway becomes obstructed.

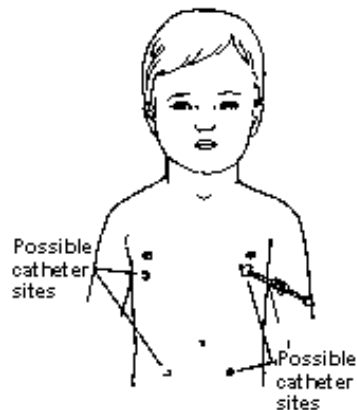
Figure 10: CPAP - Continuous positive airway pressure device for pediatric patients



## Central Intravenous Catheters

A central intravenous catheter is used to deliver nutritional substances or special medications directly into a central vein. Catheter tubes may be located on the chest, neck, groin, or arm. See *Figure 11: Central Intravenous Catheters*

Figure 11: Central Intravenous Catheters - Sites for internal and external intravenous catheters



## **Types of Central Intravenous Catheters**

- ❖ *BROVIAC*® catheters - This type usually exit the skin in the chest region; there is usually a cap at the end and a clamp that closes flow to and from the vein.
- ❖ *HICKMAN*® catheter - Usually connect to a pouch under the skin in the chest region; you may see a slight bulge where the pouch is located.

## **Central Intravenous Catheter Management**

Whenever assessing a child, who has a central intravenous catheter, check the site where the tube is placed to see if it appears clean and well-maintained.

- ❖ If the catheter is dislodged or broken, control bleeding if present and transport.
- ❖ If the catheter has been completely pulled out and there is bleeding at the entry site, apply direct pressure to the site using a sterile dressing.
- ❖ If the catheter is present and there is bleeding around the entry site, apply direct pressure around the catheter using a sterile dressing.
- ❖ If the child is bleeding through a damaged catheter, clamp the exposed end of the tube. Never leave a central IV open, as air could enter the bloodstream through the catheter, a life-threatening complication.

Estimate the amount of blood the child has lost and relay this information to the emergency department staff. Assess breath sounds carefully. Internal bleeding can lead to a hemothorax and breathing problems. Provide appropriate treatment if the patient shows signs of respiratory distress or shock.

If nutrients or medications will not flow through the catheter, it may be obstructed, provide transport.

Blood clots can form inside the catheter and break off, blocking blood flow to significant organs. In this case, the child may have altered mental status, signs of respiratory distress, or signs of shock and should be transported immediately for further evaluation.

Children with central IV's are at high risk for bloodstream infections, this should be suspected if the child has a fever.

If the child depends on the central IV for delivery of nutrients and glucose, transport the child with the catheter in place if possible. Some children have difficulty tolerating even brief periods in which nutrient delivery is interrupted. Ask the parents or home care provider for assistance.



## **Pacemakers**

Pacemakers regulate the heart rate. A pacemaker may be needed if the natural heart rate is not fast enough to maintain adequate perfusion, or if there are periods when the heart rate is too fast or too slow. The pacemaker controls the heart's pumping activity to correct these problems.

Pacemakers usually include the following parts:

- ❖ *Generator* - produces the electrical charge that causes the heart to contract.
- ❖ *Controller* - contains the circuitry that senses the heart's natural activity and decides when the pacemaker should fire.
- ❖ *Leads* - connects the generator to the heart, through which electrical current is delivered when the pacemaker fires.

Types of pacemakers include:

- ❖ *Demand* - senses the heart's natural rhythm and fires when the heart rate falls below a preset minimum.
- ❖ *Constant* - works at all times to maintain a constant heart rate; some models can also sense when a faster heart rate is required and adjust the rate accordingly.
- ❖ *Anti-arrhythmia* - senses the heart's natural rhythm and fires when an abnormally fast or slow heart rate is detected.

## **Management Considerations**

Emergency providers should ask the patient's parents or home care provider about the nature of the child's heart problem and the type of pacemaker in place. The type of pacemaker in use will depend on the child's heart problems. If the parents are not available, check for a medical bracelet, identification tag or clinical information folder.

The following considerations affect assessment and management of children with pacemakers:

- ❖ These children may progress very rapidly from early shock to late shock. This is because the pacemaker will not allow the heart rate to increase in response to early shock. If a child with a pacemaker shows signs of shock or has the potential to develop shock, consider the child's condition urgent and transport immediately.
- ❖ If the pacemaker fails, the child's heart rate may become too slow to maintain perfusion, which can result in immediate shock.
- ❖ If during assessment you find that the child's heart rate is abnormally fast or slow, the pacemaker may be malfunctioning. This condition also calls for rapid transport.

### ***Children with Special Health Care Needs***

- ❖ Occasionally, the pacemaker leads may become dislodged, contacting with the child's diaphragm instead of the heart. This will make the diaphragm contract each time the pacemaker fires. Children experiencing this problem usually have periods of fast breathing with no other sign of respiratory distress. The respiratory rate will equal the pacemaker's preset rate.
- ❖ Pacemaker leads may break when a child experiences a traumatic injury, leaving the child susceptible to the heart problem normally controlled by the device. Because of this risk, pay particular attention to circulatory assessment when a child with a pacemaker suffers a traumatic injury.

## **Feeding Catheters**

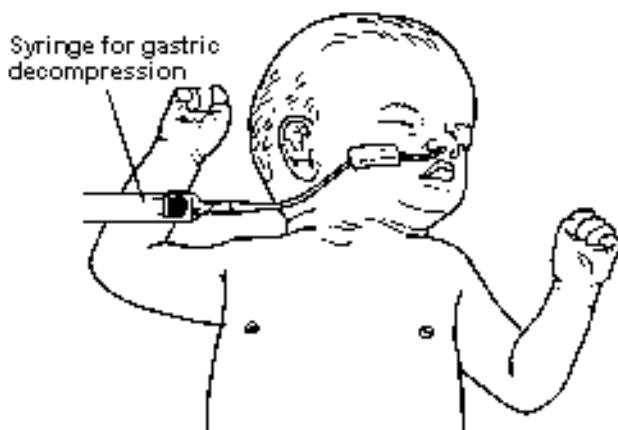
A feeding catheter is designed to manage nutritional needs in a child who requires supplemental nutrients or who is unable to take in food by mouth. Feeding catheters may also be used to administer medications. If a child requires a feeding catheter for a relatively brief period, the catheter is run through the mouth or nose into the stomach or jejunum, a portion of the small intestine. These catheters may be left in place up to a few weeks. If the child requires a feeding catheter for longer periods, the catheter is surgically implanted. In this case, the device passes through the skin and into the stomach or small intestine. Children who have one of these devices will have a button, valve, or tube in the abdominal area.

### **Non-Surgical Feeding Catheters**

There are four common types of feeding catheters for short-term use:

- ❖ Nasogastric Tube (NGT) - runs through the nose into the stomach. See *Figure 12: Nasogastric Tube*
- ❖ Nasojejunal Tube (NJT) - runs through the nose into the small intestine, presenting less risk of aspiration than a Nasogastric Tube.
- ❖ Orogastric Tube (OGT) and Orojejunal Tube (OJT) - which run through the mouth into the stomach or small intestine, respectively; these catheters are used when it is not possible to place a nasal tube.

Figure 12: Nasogastric Tube - Nasogastric Tube with syringe attached for stomach decompression



### **Surgical Feeding Catheters**

There are three common types of surgically inserted feeding catheters:

- ❖ Gastrostomy Tube (GT) - passes through the abdomen into the stomach. See *Figure 13a: Gastrostomy Tube*
- ❖ Jejunostomy Tube (JT) - passes through the abdomen into the small intestine.
- ❖ Percutaneous Endoscopic Gastrostomy (PEG)- also called a button, which is similar to the Gastrostomy Tube but is equipped with a cap and valve. See *Figure 13b: Gastrostomy Tube and Peg*

### **Management Considerations**

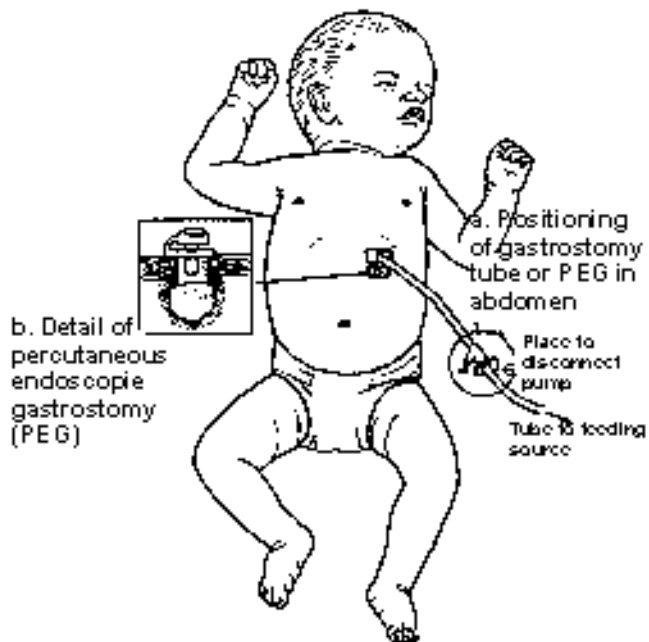
When examining a child with a surgically implanted feeding tube, check for irritation and bleeding at the site where the tube enters the skin. Treat minor bleeding with direct pressure and sterile dressings. A leaking feeding tube may cause skin irritation. This is a non-urgent problem that should be assessed by the patient's physician. If there are any signs of infection at the entry site, the child should be transported for further medical attention.

### **Children with Special Health Care Needs**

- ❖ If the feeding tube adapter breaks, transport the child so that nutrient delivery can resume as soon as possible.
- ❖ If an oral or nasal feeding catheter is interfering with assessment and lifesaving interventions in a critically ill or injured child, or if the catheter has become partially dislodged, remove it without harming the child. Be sure to report this circumstance to the receiving emergency department personnel so the catheter can be replaced.
- ❖ If a surgically implanted feeding tube is pulled out, transport the child to an emergency room.
- ❖ Feeding tubes may be attached to a pump that delivers a set volume of fluid per hour. The pump can be disconnected if necessary to provide patient care and transport.

If a child who is receiving assisted ventilation has a nasogastric or orogastric tube in place, use the tube to decompress the stomach. This will relieve pressure on the diaphragm with little danger of the child aspirating stomach contents. Surgically placed feeding tubes may also be used for stomach decompression during bag-valve-mask ventilation, however you need to ask the parents or home care provider for a special adapter to do this.

Figure 13a-b: Gastrostomy Tube and PEG



## **Cerebrospinal Fluid (CSF) Shunts**

A variety of medical problems can lead to placement of a special catheter to drain excess cerebrospinal fluid from the brain. This type of catheter is called a cerebrospinal fluid (CSF) shunt . It runs from the ventricles in the brain, under the skin from the skull, to the chest or abdomen. It can be felt as a bump under the skin of the head and neck. *See Figure 14:CSF Shunt*

### **Management Considerations**

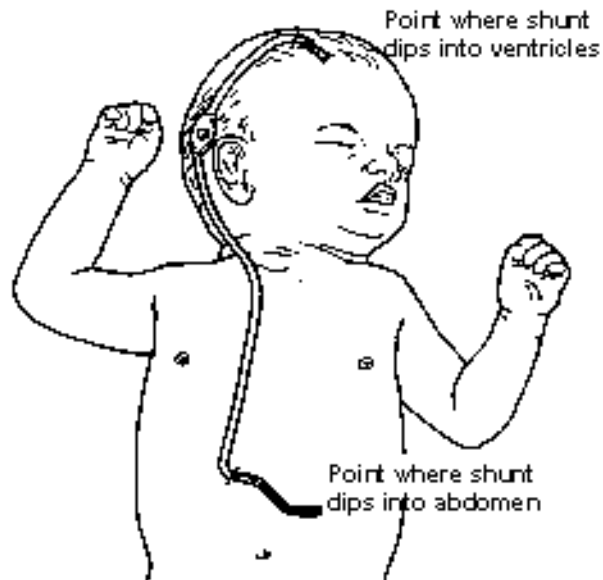
The child with a CSF shunt is vulnerable to brain infections. Additionally, the shunt can develop an obstruction, resulting in a dangerous buildup of fluid within the skull. If a child with a CSF shunt has any of the following signs or symptoms, provide appropriate initial interventions and transport:

- ❖ Altered mental status
- ❖ Listlessness
- ❖ Increased sleep
- ❖ Nausea or vomiting
- ❖ Fever
- ❖ Headaches
- ❖ Difficulty walking
- ❖ Apnea
- ❖ Seizures
- ❖ Rapid worsening of mental status

Emergency providers should:

- ❖ Maintain a patent airway.
- ❖ Provide high-flow oxygen, positive pressure with bag-valve-mask if necessary.
- ❖ Rapid transport.

Figure 14: CSF Shunt - Placement of cerebrospinal fluid shunt



## **Colostomies and Ileostomies**

In a colostomy or ileostomy, a portion of the large or small intestine is attached to a surgical opening in the abdominal wall, and an external bag is placed to collect digestive waste matter. This intervention may be necessary due to traumatic injury or a variety of medical problems. See *Figure 15: Infant Patient with Colostomy*

### **Management Considerations**

A child who has a colostomy or ileostomy is at risk for dehydration. Assess carefully for signs of dehydration and shock, particularly if there is any history of diarrhea or decreased oral intake. Check the ostomy site for signs of infection or irritation. Signs of infection include red, warm, tender skin spreading away from the site. Ask the child or parents if the area is more tender than usual. If the child has signs of infection, transport the child for further evaluation.

If the child's collection bag breaks, the parents or home care provider can usually help replace it. If another bag is not available, circle the ostomy with moist gauze and attach any available bag that can serve as a substitute until a proper replacement bag is obtained.

Figure 15: Infant Patient with Colostomy



## **Special Patients**

### **Mental Retardation (Cognitive Impairment)**

Mental Retardation is the most common developmental disability in the United States, affecting some 3% of the population. The definition of Mental Retardation is “significantly sub-average general intellectual functioning”. The majority of those individuals with this condition acquired it through a genetic abnormality. Some of the genetic disorders that contribute to cognitive impairment are: Down’s Syndrome, Fragile X Syndrome and Prader-Willi Syndrome.

Mental Retardation is a permanent condition of impaired cognition. Although some individuals with this disorder can overcome their disability to a certain degree and improve their quality of daily living, they remain cognitively impaired for their life span. Children with cognitive impairment may look very normal in their physical appearance or they may show signs of obvious physical markers for mental retardation such as: obesity, facial abnormalities or cranial abnormalities.

Emergency providers should practice a sensitive approach to children with mental retardation. Ask for the child's name and use it in conversation. Refer to the patient as a "special child" rather than using terms like "retarded" or "slow."

#### **Assessment Considerations:**

Assess the child accurately, ask the parents or home care provider about the child's usual abilities and behavior in the following areas:

- ❖ Mental or cognitive development
- ❖ Interaction with parents
- ❖ Interaction with strangers
- ❖ Communication abilities
- ❖ Motor development - ability to sit, stand, and walk
- ❖ Muscle tone and strength
- ❖ Vision and hearing

Ask the parent whether the child's overall behavior seems different from usual. This information will give you the basis to judge how seriously the child is affected by the current illness or injury. Interact with the child in an age-appropriate manner. Keep in mind that children with mental retardation may act younger than their age. Talking to the parents and involving them in the care of the child, as much as possible, will help put the child at ease.



## **Developmental Delay (Maturational Lag)**

The overall growth and development of children is measured in levels of developmental accomplishments within each specific age group. Each developmental “milestone” builds on the previous age group accomplishments. In the chronically ill child, these “milestones” may be delayed due to the nature of their illness and other factors, such as prolonged hospitalization. The chronically ill child may fall behind in normal developmental parameters for their specific age group, but often catch up with assistance and improvement in their health condition.

Maturational lag should not be confused with mental retardation. Mental retardation is a permanent condition of cognitive impairment that is present at birth. Developmental delay is the result of a lack of exposure to the usual developmental environment that healthy children are exposed to everyday. Although some of the delays may remain permanent conditions, the majority of children exhibiting the signs and symptoms of maturational lag overcome these shortcomings and eventually mature normally.

Although you may have to approach the developmentally delayed child from an specific age group level that is younger than their chronological age, you should involve the child in as many aspects of their assessment and health care as possible. It will give them a heightened sense of accomplishment to participate in their own health care.

### **Assessment Considerations:**

Assess the child accurately, ask the parents or home care provider about the child's usual abilities and behavior in the following areas:

- ❖ Mental or cognitive development
- ❖ Interaction with parents
- ❖ Interaction with strangers
- ❖ Communication abilities
- ❖ Motor development - ability to sit, stand, and walk
- ❖ Muscle tone and strength
- ❖ Vision and hearing
- ❖ Retention of learned skills
- ❖ Knowledge level of healthcare problems

Ask the parent whether the child's overall behavior seems different from usual. This information will give you the basis to judge how seriously the child is affected by the current illness or injury. Interact with the child in an age-appropriate manner. Keep in mind that children with maturational lag may act younger than their age. Talking to the parents and involving them in the care of the child, as much as possible, will help put the child at ease.

## **Premature Babies**

A baby who is born prior to 37 weeks gestation is considered a premature baby. When providing emergency care for a premature infant, providers should keep the following points in mind:

### Management of a Premature Baby At The Time Of Delivery

- ❖ Hold the infant at level of mother's pelvis.
  - ❖ Suction mouth and nose with bulb syringe (suction mouth before nose).
  - ❖ Tie/clamp and cut cord (leave 3 inches between ties/clamps).
  - ❖ Dry, warm and vigorously stimulate the infant (replace wet towels/blankets).
  - ❖ Place infant on a flat surface in the air-sniffing position.
  - ❖ Open the airway with jaw-thrust maneuver.
  - ❖ Look, listen and feel for spontaneous respirations.
  - ❖ Keep the baby warm at all times, remembering to cover the head.
- 
- ❖ If dusky but pulse greater than 100, administer blow-by oxygen (if available) and continue stimulation.
  - ❖ If pulse is less than 100, respirations are irregular, or muscle tone or color is poor, provide positive pressure ventilation and oxygen (if available).
  - ❖ If pulse remains less than 100 despite positive pressure ventilation, endotracheal intubation by an advanced life support trained individual will be necessary.
  - ❖ If pulse is less than 60 (or 60 - 80 and not increasing), administer chest compressions, consider a saline bolus and administer appropriate medications (at the discretion of the receiving facility - must be provided by advanced life support personnel.)

Pay special attention to suctioning if the baby shows any sign of respiratory distress. Do not suction the airway for more than ten seconds, and watch the infant carefully throughout the process. Stop suctioning if the baby begins to turn pale or blue, or if the heart rate slows.

### **Conditions of Prematurity**

Babies that are born premature can have numerous health problems during birth and after going home from the hospital. When responding to a child with a history of prematurity, ask the parents whether the child has any medical problems, if the baby depends on any special medical devices, or is on any medication. Provide appropriate interventions for problems involving these devices.

Some of the conditions of prematurity that may be encountered when responding to a child with a history of prematurity include:

Bronchopulmonary Dysplasia (BPD) – usually caused by prolonged exposure to mechanical ventilators, high concentrations of oxygen and endotracheal intubation. Delicate alveolar tissues are scared and damaged.

Apnea of Prematurity – persistent apneic spells lasting for 20 seconds or longer with the possibility of bradycardia and color changes.

Hemorrhagic Disease of the Newborn – related to a vitamin K deficiency. Vitamin K is necessary for blood clotting. May be responsible for bleeding in any organ of the body.

Patent Ductus Arterious (PDA) – failure of the fetal ductus arterious (artery connecting the aorta and pulmonary artery) to close within the first few weeks of life. Results in a shunting of blood from the aorta to the pulmonary artery. It results in congestive heart failure.

Anemia – a lack of circulating red blood cells. Can occur for various reasons. Results in a decrease in the oxygen caring capacity of the blood. Will result in hypoxia in all cells of the body.

Intracranial Hemorrhage – various causes. Infant may appear to have suffered a stroke or to exhibit other various neurological deficit signs and symptoms.

As with all patients experiencing medical emergencies airway, breathing and circulation should be the priority. The parents will be under a great deal of stress, remember to be supportive and understanding.

## **Children with Congenital Heart Disease**

These children are born with a structural abnormality affecting the heart. Congenital heart disease may involve:

- ❖ Heart valve problems that prevent blood from pumping out of the heart properly or allow some blood to flow back into the heart when it pumps; this can lead to inadequate perfusion, making the child susceptible to shock and a lack of oxygen in the cells and tissues.
- ❖ Problems in which the pulmonary arteries do not bring enough oxygenated blood to the heart putting the child at risk for heart attacks during the first weeks after birth.
- ❖ Cyanotic heart disease causes blood from the veins and the arteries to mix together resulting inconstant low blood oxygen levels.
- ❖ Problems caused from disorders with the electrical stimulation of the heart can cause

the heart to beat irregularly.

## **Management of Children with Congenital Heart Disease**

When providing care for children with congenital heart disease, emergency providers should remember the following:

These children may have constant low-blood oxygen levels, so the respiratory problems are more dangerous to them than to healthy children.

- ❖ Provide aggressive treatment for any breathing difficulties.
- ❖ Offer oxygen if tolerated by the child, position appropriately, and begin positive pressure ventilation for apnea, gasping, or cyanosis.

Since the heart does not pump efficiently, shock presents a greater risk than in a healthy child.

- ❖ Watch for signs of shock and treat appropriately.
- ❖ Provide a fluid bolus of 20 cc/kg of Normal Saline or Ringers Lactate if indicated. Can be repeated at same dose if there is some response to first bolus, or no response and severe fluid loss is obvious. (Must be provided by certified or licensed personnel.)
- ❖ Utilize extreme caution when administering IV fluids to the chronic cardiac patient due to excessive fluid administration leading to fluid overload.
- ❖ Assess for fluid overload or pulmonary edema frequently.

The most common pediatric dysrhythmias are bradycardia, tachycardia, asystole, and Pulesless Electrical Activity (PEA).

- ❖ Many of these children are treated with Digoxin/Lanoxin. Children should be placed on a cardiac monitor and closely monitored for lethal cardiac dysrhythmias.
- ❖ Once a dysrhythmia is identified on the cardiac monitor, follow approved guidelines and treatment protocols.

## **Children with Mobility Problems**

Spasticity, muscle/limb contractures or paralysis can cause mobility problems.

Children with paralysis, spasticity or muscle/limb contractures present special challenges when positioning them for immobilization or transport. Attempt to position the child in a way that is comfortable for them. Remember to always pad all voids, pad under bony prominences (these children usually lack adequate protective fat pads) and utilize pillows and blankets/towels to support contracted limbs when immobilizing or transporting these special children.

Spasticity is a condition in which the muscles and tendons become tight, restricting movement of joints and extremities (contractures) or the muscles have an abnormal involuntary movement. While the condition does not affect most assessment and management procedures, the condition will present a problem in positioning and transport because most of these children are unable to be placed on a long spine board as in the case of trauma. Try to achieve a position of comfort for the child. The parents or home care provider may be able to help determine the best approach for positioning. Never force a child into an uncomfortable or even painful position.

Children with paralysis pose similar problems regarding positioning. Additionally, since most of these children cannot feel anything in the paralyzed areas, they cannot report pain in these areas. Try to compensate for this during assessments for injury by examining carefully for signs of physical abnormalities. Also remember to utilize extreme caution when moving and handling these children. Because they cannot feel pain, they do not respond to injuries the way feeling patients can. They could accidentally be injured but can not respond as feeling patients would.

### **Conditions Causing Problems with Mobility**

Cerebral Palsy (CP) – Cerebral Palsy is the most common permanent disability of movement in children. It is due to various types of injury to the brain before, during or after delivery, it presents with various forms of abnormal muscle tone and coordination. It results in various types of mobility dysfunction: spasticity, contracted limbs, involuntary muscle contractions, ataxic gait, involuntary jerking, and unconscious repetitive movement.

Osteogenesis Imperfecta/Brittle Bone Disease (OI) – This disorder causes the child to have osteoporosis and makes them very susceptible to fractures. Even the gentlest handling can cause a fracture to occur.

Spina Bifida – Term most commonly utilized to describe the congenital birth defects of neural tube closure. The spine and spinal cord are formed during the first six weeks of gestation. In some instances the spinal column fails to close around the spinal cord, leaving it exposed and unprotected. The spinal cord bulges through the opening in the vertebral bones. It can be as minor as a small portion of the vertebral bone not developing to an entire portion of the spinal cord protruding through the skin on the back. Another severe secondary condition, Hydrocephalus, or increased production of cerebral spinal fluid can be present.

The three most common forms of Spina Bifida are:

Spina Bifida Occulta – Failure of the posterior vertebral bone to close completely without herniation of the spinal cord or meninges through the opening of the bone. Many

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### ***Children with Special Health Care Needs***

individuals have this condition and are never aware of it. There are no serious manifestation with this form of Spina Bifida.

Meningocele – Failure of the posterior vertebral bone to close completely with the meninges, or protective cover of the spinal cord, protruding through the opening in the vertebra and the skin of the back, forming a sac called a meningocele. Rarely is the spinal cord involved. It can be repaired with little or no damage to the spinal cord.

Myelomeningocele – The most severe form of Spina Bifida. A portion of the spinal cord actually protrudes through the back. In some cases it is covered with a protective sac. In other cases, the tissue and nerves are exposed completely. These patients are the ones who suffer from paralysis and hydrocephalus. The level of paralysis will depend on the location of the defect. Spina Bifida can occur along any portion of the spinal column. Most Myleomeningoceles occur in the lumber and sacral regions of the spinal cord. This results in loss of bladder and bowel control and paralysis to the lower limbs. Because of the excessive amount of cerebral spinal fluid produced with this type of defect, the patient usually has to have a CSF shunt inserted to prevent a serious build up of cerebral spinal fluid and increased intracranial pressure in the skull.

### **Wheelchairs**

Many children with special conditions of mobility utilize special wheelchairs. Although, it is probably the optimum way to transport these special patients, most ambulances do not have the proper locking devices to safely secure these special wheelchairs for transport. Unless the transport vehicle is properly equipped to safely transport these special wheelchairs, all of these children should be transported on a stretcher with safety straps in place and proper support padding utilized.

### **Children with Chronic Illness**

Some children may have a continuing or chronic illness that affects them at all times. Chronic conditions do not usually require emergency care; however, children with chronic illness may have medical emergencies for other reasons:

- ❖ They may experience an unrelated illness or a traumatic injury
- ❖ They may suffer a sudden worsening of the underlying chronic condition

### **Management Considerations**

Assessment and management of children with chronic illness generally follows the same guidelines as for well children. However, you should remember the following:

- ❖ The child's baseline vital signs may be different from those for a healthy child of the same age. Ask the parents or home care provider for information about the child's usual

### ***Children with Special Health Care Needs***

vital signs. Combine this information with other initial assessment findings to determine the child's CUPS status.

- ❖ Since these children may have decreased ability to tolerate illness or trauma, monitor them closely at all times for signs of deterioration.
- ❖ Emergency providers may be called only after the child has received significant medical treatment at home. This may mean that the child is in a later stage of illness or injury by the time EMS arrives than would be the case in healthier children with similar complaints.
- ❖ Question the parents or home care provider about how the child usually acts and feels. Also ask about interventions and treatments that have already been provided prior to the emergency providers arrival. This will help judge how greatly the child is affected by the current illness or injury.

## **Common Chronic Illnesses**

### **Chronic Lung Diseases/Disorders**

**Bronchial Asthma** – Responsible for more absences from school than any other disease process. It is responsible for the majority of pediatric hospital admissions and is believed by many to be the single most important cause of death in childhood. Asthma is a condition that increases the responsiveness and irritability of the lower airways. This causes the airways to constrict and decrease the amount of air and oxygen that can enter and exit the lungs. It is believed that asthma's primary cause is allergy related. A hypersensitivity to foreign substances, such as pollen, increases the chances of an asthmatic response if exposed to an allergen.

**Reactive Airway Disease** – Similar to Asthma, Reactive Airway Disease is a man made disease. With the increase of industrial air pollution, carbon monoxide released by cars, chemicals in the home and other air pollution, there has been an increase in children experiencing respiratory distress, when exposed to these airway irritants. It presents with symptoms similar to Asthma, wheezing, shortness of breath, cough and increased work of breathing. It is treated the same way as Asthma, oxygen and medications. As the pollution in our air increases, so will the incidence of Reactive Airway Disease cases.

**Congestive Heart Failure (CHF)** – In children, CHF frequently occurs secondary to structural abnormalities of the heart that result in increased blood volume and blood pressure. It is usually caused by increased work on the heart. There are multiple defects that children can be born with that will contribute to CHF. The inability of the heart to circulate blood properly causes a back up of fluid into the lungs. This fluid is called Pulmonary Edema. In children, CHF is usually treated with digitalis glycosides (Digoxin/Lanoxin). Monitor these patients closely for signs of dysrhythmias.

## **Cystic Fibrosis**

Cystic Fibrosis (CF) – The most common serious pulmonary and gastric disease in children. It is a multi-system disorder affecting the exocrine glands (mucous producing) glands and accounts for a large percentage of lung disease in children. The primary disease mechanism is mechanical obstruction of the lungs and gastrointestinal tract by increasing the thickness of mucous produced in these two systems. In the GI tract, the most common complication seen is a bowel obstruction, which is a true emergency. If not detected and relieved promptly, a bowel obstruction could cause the bowel to rupture. This could lead to death rapidly. Pulmonary complications constitute the most serious threat to life. Because of the buildup of thick, viscous mucous in the bronchus and bronchioles, the child is unable to cough it up. The retained mucous is an excellent medium for bacterial growth. It also interferes with oxygen and carbon dioxide exchange causing various degrees of hypoxia, hypercapnia and acidosis. During a crisis, the focus is on supporting respiration and oxygenation.

When responding to children with chronic illnesses of the respiratory tract, support them with high concentrations of oxygen, assist ventilations with a bag valve mask if needed, administer medications and perform endotracheal intubation if necessary, as directed by receiving facility.

## **Diabetes Mellitus (DM)**

Diabetes Mellitus is the most common endocrine disorder in children. It is characterized by a deficiency in the production of the hormone Insulin by the pancreas. It can be classified into three major groups:

Insulin-dependant (IDDM) or type I – child needs daily injections of Insulin to regulate the metabolism of glucose.

Non-Insulin-dependant (NIDDM) or type II – child may or may not need daily injections of Insulin to regulate the metabolism of glucose. It is usually controlled with diet.

Maturity-onset-diabetes of youth (MODY) – developed late in adolescence. Child may or may not need injections of Insulin to regulate the metabolism of glucose. Usually controlled by diet and/or oral medication.

Insulin-dependant diabetes or IDDM is the most common form of diabetes in children. The two most serious complications of Diabetes in children are: hypoglycemia and ketoacidosis.

It is important to check glucose levels in all children with a history of Diabetes. Stress, infectious processes and other factors will contribute to the depletion/elevation of glucose levels in the diabetic child. Assure obtaining a good history from the parents or health care



provider about meals and Insulin administration.

If it is determined that the child has hypoglycemia it may be necessary to administer glucose. If it is determined that a child has a glucose level of 200 or higher, with a fruity odor to their breath and evidence of hyperventilation, the child should be considered in ketoacidosis. Therapy in the field should consist of high concentrations of oxygen, assist ventilations as needed and the administration of intravenous fluids. It is also important to monitor the cardiac rhythms of the diabetic child. These children can suffer from severe dehydration as a result of polyuria (excessive urination) and their potassium levels can be severely altered. This could lead to potentially lethal dysrhythmias. Another condition secondary to polyuria is hypovolemia, monitor the child's skin, capillary refill, distal pulses, mental status, and blood pressure carefully to discover the early signs of volume depletion and treat accordingly.

### **Gastrointestinal (GI) Dysfunction**

There are multiple disorders of the GI tract that can become chronic disease processes. Some of these will eventually lead to colostomies or ileostomies in the pediatric patient.

#### **Crohn's Disease**

A chronic inflammatory process of the GI tract that can involve any part, from the mouth to the anus. Inflammation eventually leads to severe edema and deep ulcers in the intestinal wall. These ulcers can lead to rupture or obstruction of the GI tract. This can be a truly life threatening situation. Diet and medications typically control this disorder. When diet and medication can no longer control the disease process, surgery is the only solution. A colostomy or an ileostomy will be performed as a last resort. The performance of surgery however, will not halt the disease process. Over time this surgery will have to be repeated multiple times.

#### **Ulcerative Colitis**

A less severe disease process, Ulcerative Colitis effects only the colon and the rectum. Inflammation, edema, bleeding and ulceration of the walls of the colon and rectum characterize it. This disease process leaves the colon and rectum narrowed by scar tissue and effects the GI tract ability to function properly. Unlike Crohn's Disease, performing a total colectomy (complete removal of the colon) will cure this disease process. Trying to control the disease with diet and medication are always tried first.

#### **Failure to Thrive (FTT)**

Inadequate growth resulting from the inability to obtain and/or use calories required for growth. Failure to thrive can be related to the chronic disease process of the child. Often they are unable to take in the proper amount of nutrients or process these nutrients, for various reasons, to grow and develop adequately. These children may appear

### ***Children with Special Health Care Needs***

malnourished and wasted, even when they are properly fed. Utilize extreme caution, not to jump to the conclusion of child neglect.

#### **Mal-absorption Syndrome**

Mal-absorption Syndrome is a group of disorders, which for various reasons prevent the child from absorbing the proper nutrients (proteins, simple sugars, fats, etc.), in the gastrointestinal tract. The outward signs can be anything from a potbelly and wasted limbs to extreme signs of malnutrition.

#### **Cystic Fibrosis (CF)**

The primary concern for the cystic fibrosis patient involving the gastrointestinal tract is bowel obstruction by thick mucous production. Bowel obstruction is a life-threatening emergency. If the child exhibits severe abdominal pain and/or absent bowel sounds, assume that a bowel obstruction has occurred until it can be ruled out. Support airway, breathing and circulation and transport rapidly to the closest appropriate facility.

#### **Sickle Cell Anemia (SCA)**

Named for the unique sickle shaped red blood cells it creates, Sickle Cell Anemia can reduce the oxygen carrying capacity of the red blood cells and can cause loss of blood flow to the vital organs of the body. The unique sickle shape of the red blood cell increases the friction of circulating blood. This causes increased thickness to the blood. This slows the circulation and causes stoppage of the blood flow in organs. The sickle shaped cells can clump together and block adequate blood flow to the tissues and organs causing severe pain. This causes scarring and tissue death in the affected organs. The red blood cells also have a shorter life span than normal red blood cells. This decreases the oxygen carrying capacity of the red blood cells, resulting in anemia.

The most acute symptoms of the disease occur during periods of worsening of the child's condition called a Sickle Cell Crisis. Stress, infection or cold, high altitude environments usually bring on these crises. The symptoms of a crisis may include: severe pain, fever, edema to the hands and feet, painful joints, severe abdominal or chest pain, non-productive cough, slurred speech, altered mental status, visual disturbances, blood in the urine, priapism (in the male patient) and paralysis on one side of the body.

The two most serious complications of Sickle Cell Anemia is chest syndrome (chest pain, fever and dry, hacking cough) and stroke. Stroke can be a fatal consequence of Sickle Cell Anemia.

The care of the Sickle Cell patient is mostly supportive, high concentrations of oxygen, assist ventilations if necessary, and pain medications at the discretion of the receiving facility.

## **Seizures**

Convulsions are among the most frequently observed neurologic dysfunctions in children. Seizures in children may be caused from: high fevers, exposure to chemicals and toxins, hypoxia, electrolyte imbalances, head trauma, brain tumors, increased intracranial pressure, infections, hypo/hyperglycemia and epilepsy.

There are many types of seizures with the most common being tonic-clonic. This is when the entire body convulses and there is a brief period of unconsciousness afterwards. Petit Mal seizures or absence attacks are characterized by brief periods of disorientation or staring spells. This type of seizure can be missed as they are usually attributed to daydreaming or inattentiveness. Partial seizures can affect just one part of the body like the face or just one arm. Psychomotor seizures in children are bizarre in appearance and the child may appear to be chewing, smacking their lips or swallowing over and over again. They may also start running, kicking, laughing or speaking incoherently. Special sensory seizures are characterized by various sensations such as numbness, tingling, prickling, paresthesia, or pain in one part of the body that spreads to other body parts.

Regardless of the type of seizure a child may have, the primary care goals are to protect the child from hurting themselves, and support airway, breathing and circulation. Never restrain a child while they are actively seizing. Move objects that the child may strike, while seizing, away from them so they do not hurt themselves. **Never place objects into a patient's mouth who is actively seizing.** If you want to protect their airway, gently roll them onto their side in the recovery position. This will prevent the tongue from blocking the airway and prevent them from aspirating fluids into their lungs. Monitor the airway for blood (from biting their tongues) and other secretions. Suction the airway as soon as the seizure has stopped. Be alert for another seizure at all times. Continuous seizures without the patient regaining consciousness or a seizure that sustains and doesn't stop is known as "Status Epilepticus" and is a medical emergency. Transport this patient rapidly to the closest appropriate facility. For the advanced health care provider, utilize the appropriate medications to control seizure activity at the discretion of the receiving facility.

## **Genitourinary Dysfunction**

### **Nephrotic Syndrome/Glomerulonephritis**

Nephrotic Syndrome occurs as a result of damage to the primary organ of function in the kidneys called the Glomerulus. Damage can be caused by exposure to toxic chemicals, congenital abnormalities or infectious processes. In Nephrotic Syndrome the glomerulus become unable to hold large protein molecules in the blood as it filters through the kidneys. Because the protein molecules are not maintained in the circulating blood, it affects the osmotic pressure in the capillary beds and fluid leaks out into the tissues and body cavities

causing edema. The edema can also effect the lungs causing fluid to back up into the

lungs. This loss of fluid from the vascular space can also cause hypovolemia in the child with Nephrotic Syndrome.

### Renal Failure

For various reasons, pediatric patients may suffer from renal failure. The kidneys produce little or no urine and a serious build up of toxins in the body and other serious health conditions may result. Some of these health conditions are:

**Hyperkalemia/High Potassium Levels** – a serious life threatening condition that could cause the child to experience lethal cardiac arrhythmias.

**Hypertension** – the kidney plays a major role in the regulation of blood pressure. The renin-angiotension system helps to control blood pressure by regulating water balance in the body. If the kidneys fail to function normally this system fails to operate properly.

**Seizures** – as toxins build up in the body and are not eliminated by the kidneys, a condition known as uremia develops. These toxins will lead to seizures if not eliminated.

**Cardiac Failure** – as the kidneys become unable to eliminate fluid from the body, it begins to back up into the tissues of the body (hypervolemia), including the lungs. The result is the condition of Pulmonary Edema. This fluid backup in the body and lungs puts more stress on the heart. Cardiac failure is ultimately the cause of death in the Renal Failure patient.

### **Indwelling Urinary Catheters**

Many children with chronic illnesses experience an inability to control their urinary elimination. Whether it is because of paralysis, chronic immobility due to the nature of their illness or other reasons, they require a urinary drainage catheter to help eliminate urine from their bodies. These catheters pose no problem in and of themselves; however, they can be a primary source of infection if they are not maintained properly. When caring for a child with a urinary catheter be alert for the signs of an infection such as: dark colored urine, foul odor, cloudy appearance to the urine, material floating in the urine, blood in the urine and fever.

When caring for the patient with urinary system disorders, the priority is as usual, airway, breathing, and circulation. Support with high concentrations of oxygen, assist ventilations as necessary, restrict the introduction of IV fluids to children who show signs of fluid overload, swollen feet, hands and face, and monitor their cardiac status very closely.

## **Traumatic Brain Injury**

A traumatic brain injury (TBI) is an injury to the brain caused by the head being hit by something or shaken violently. This injury can change how the person acts, moves, and thinks. A traumatic brain injury can also change how a student learns and acts in school. The term TBI is used for head injuries that can cause changes in one or more areas, such as thinking and reasoning, understanding words, remembering things, paying attention, solving problems, thinking abstractly, talking, behaving, walking and other physical activities, seeing and/or hearing, and learning. The term TBI is not used for a person who is born with a brain injury. It also is not used for brain injuries that happen during birth.

More than one million children receive brain injuries each year. More than 30,000 of these children have lifelong disabilities as a result of the brain injury.

The signs of brain injury can be very different depending on where the brain is injured and how severely. Children with TBI may have one or more difficulties, including

- ❖ **Physical disabilities:** Individuals with TBI may have problems speaking, seeing, hearing, and using their other senses. They may have headaches and feel tired a lot. They may also have trouble with skills such as writing or drawing. Their muscles may suddenly contract or tighten (spasticity). They may also have seizures. Their balance and walking may also be affected. They may be partly or completely paralyzed on one side of the body, or both sides.
- ❖ **Difficulties with thinking:** Because the brain has been injured, it is common that the person's ability to use the brain changes. For example, children with TBI may have trouble with short-term memory. They may also have trouble with their long-term memory. People with TBI may have trouble concentrating and only be able to focus their attention for a short time. They may think slowly. They may have trouble talking and listening to others. They may also have difficulty with reading and writing, planning, understanding the order in which events happen and judgement.
- ❖ **Social, behavior, or emotional problems:** These difficulties may include sudden changes in mood, anxiety, and depression. Children with TBI may have trouble relating to others. They may be restless and may laugh or cry a lot. They may not have much motivation or much control over their emotions.

A child with TBI may not have all of the above difficulties. Brain injuries can range from mild to severe, and so can the changes that result from the injury. This means that it's hard to predict how an individual will recover from the injury. Early and ongoing help can make a big difference in how the child recovers. This help can include physical or occupational therapy, counseling, and special education.

It's also important to know that, as the child grows and develops, parents and teachers may notice new problems. This is because, as students grow, they are expected to use their brain in new and different ways. The damage to the brain from the earlier injury can make it hard for the student to learn new skills that come with getting older. Sometimes parents and educators may not even realize that the student's difficulty comes from the earlier injury.

## **Appendix A: Key Points - Children with Special Health Care Needs**

- ❖ Some children with special health care needs have baseline vital signs outside the normal range for the child's age. Also, vital signs for technology-assisted children may be controlled by the child's medical device (such as a pacemaker or home ventilator). Ask the parents or check for information listing the child's baseline vital signs. If no information is available, assess the child based on normal vital signs for age.
- ❖ Parents and specially trained home care providers are an important resource in the management of children with special health care needs. They will know if the child's vital signs, assessment findings, or capabilities are different from normal. This information will help you accurately evaluate the seriousness of the child's condition. Parents can also help you with settings for medical devices and advice on transport issues.
- ❖ Children with special health care needs may have physical disabilities that make them particularly susceptible to medical problems involving the airway, breathing, and circulation. Since these children often find it difficult to tolerate respiratory distress or shock, you should consider these medical problems urgent. Technology-assisted children may also experience medical emergencies if the medical devices on which they depend fail to function properly.
- ❖ A tracheostomy is a surgical opening into the windpipe through which a tube is passed. The child then breathes through this tube. A child may have a tracheostomy to bypass an upper airway obstruction, to provide long-term breathing support using a home ventilator, or to aid in the removal of secretions.
- ❖ Types of tracheostomy tubes include the single cannula tube, which has an inner air passage inside an outer sheath; and the fenestrated tube, which has an opening through which air can be directed to the mouth and nose. The single cannula tube is most frequently encountered in children.
- ❖ You should suspect a tracheostomy obstruction if a child with a tracheostomy has any of the following findings: signs of respiratory distress; very faint breath sounds; altered mental status; lack of chest rise during assisted ventilation. To manage the obstruction, first attempt assisted ventilation through the tracheostomy tube, then suction the tube if the child does not improve. You may need to replace the tracheostomy tube if these measures are unsuccessful.
- ❖ Before suctioning a tracheostomy tube, ask the parents or home care provider for suctioning apparatus and supplies. Use a suction catheter small enough to pass easily

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into the tracheostomy tube. If possible, administer high-concentration oxygen before beginning suctioning. Loosen secretions by injecting sterile saline into the tube. Insert the catheter gently and apply suction while slowly withdrawing the catheter. Limit suctioning to ten seconds or less.

- ❖ Before removing a tracheostomy tube, ask the parents or home care provider for a replacement tube. If the existing tube has a balloon cuff, deflate it. Cut the cloth ties that hold the tube in place and remove the tube. Gently slide the new tube into place without using force. After placement, suction the tube as necessary and assess breathing to confirm proper placement. Tightly secure new cloth ties.
- ❖ A home ventilator may control the breathing rate for a child who depends on this device. You must take this factor into account during assessment.
- ❖ If a child who depends on a home ventilator shows signs of respiratory distress, ask the parents or home care provider to help you determine whether the difficulty is due to a medical condition or an equipment problem. If no equipment problem is found, or if there is an equipment problem that cannot be corrected quickly, disconnect the ventilator and provide assisted ventilation using a bag-valve device.
- ❖ If a ventilator-dependent child is breathing adequately and the ventilator is working properly, transport the child without disconnecting the ventilator. The parents or home care provider should be able to instruct you on proper transport procedures.
- ❖ A technique called continuous positive airway pressure (CPAP) may be used in children who have recurring problems with partial airway obstruction or weak respiratory effort. These children wear a device that covers the mouth and nose, providing airway pressure as the child breathes in and out. This pressure helps maintain adequate respirations and keeps the airway from collapsing.
- ❖ Many medical devices involve catheters that either deliver necessary fluids or drain fluid buildup. Central intravenous catheters deliver special nutrients or medications directly into a large central vein. Feeding catheters deliver nutritional substances or medications to the stomach or small intestine. CSF shunts drain excess fluid that would otherwise build up within the skull.
- ❖ Always assess for possible complications involving medical devices used by technology-assisted children. Central intravenous catheters can become damaged or dislodged. If bleeding occurs through a damaged catheter, you may have to clamp it. If bleeding occurs at the entry site for a dislodged catheter, you should apply direct pressure to control it. Nasogastric tubes can also become dislodged, requiring removal. Gastrostomy tubes are subject to irritation, bleeding, or infection at the entry site. A CSF shunt can develop an obstruction, resulting in pressure buildup within the patient's skull. Pacemaker leads can break, so that the pacemaker no longer regulates the heart rate. Provide initial interventions and transport for a child with any of these problems.



### ***Children with Special Health Care Needs***

- ❖ Children with paralysis, spasticity or muscle contractures may present special challenges when you must position them for immobilization or transport. As much as possible, strive for a position that is comfortable for the child. The parents may be able to advise you on how to achieve this. Remember to always pad all voids, pad under bony prominences and utilize pillows and blankets/towels to support contracted limbs.
- ❖ A child with paralysis usually cannot feel anything in the paralyzed areas and therefore cannot report pain in these areas. Try to compensate for this when assessing for injury by examining carefully for signs of physical abnormalities.
- ❖ Children with chronic illness may have different baseline vital signs from healthy children of the same age. You must take this into account when assessing these children. Their chronic illness may also make it difficult for them to tolerate new illness or injury, so you must watch them carefully for signs of worsening.

## Appendix B

<b>Medical Devices: Common Problems and Solutions</b>		
<b>Device</b>	<b>Problem</b>	<b>Action</b>
Tracheal Tube	Obstruction	<ul style="list-style-type: none"> <li>❖ Attempt assisted ventilation with high-concentration oxygen</li> <li>❖ Attempt to suction</li> <li>❖ Change tracheostomy tube</li> <li>❖ Ventilate through stoma</li> <li>❖ Transport</li> </ul>
Tracheal Tube	Dislodged	<ul style="list-style-type: none"> <li>❖ Replace tracheostomy tube</li> <li>❖ Provide assisted ventilation with high-concentration oxygen through stoma</li> <li>❖ Transport</li> </ul>
Home ventilator	Respiratory distress	<ul style="list-style-type: none"> <li>❖ Ask parents to check whether ventilator is functioning properly</li> <li>❖ Assist in adjustment of ventilator</li> <li>❖ Assess tracheostomy for obstruction</li> <li>❖ Remove patient from ventilator and provide assisted ventilation</li> </ul>
Pacemaker	Failure	<ul style="list-style-type: none"> <li>❖ Assess heart rate and perfusion</li> <li>❖ Treat for shock</li> <li>❖ Request ALS backup</li> <li>❖ Provide urgent transport</li> </ul>
Central intravenous catheter	Dislodged or damaged	<ul style="list-style-type: none"> <li>❖ Apply direct pressure to stop bleeding</li> <li>❖ Clamp or tie exposed catheter to prevent further blood loss</li> <li>❖ Assess and treat patient for hemothorax and shock</li> <li>❖ Transport</li> </ul>
Central intravenous catheter site	Signs of infection at site	<ul style="list-style-type: none"> <li>❖ Treat as potentially serious infection</li> <li>❖ Transport</li> </ul>
Oral or nasal feeding catheter	Dislodged	<ul style="list-style-type: none"> <li>❖ Remove catheter</li> <li>❖ Have patient seek medical attention</li> </ul>
Surgically placed feeding catheter	Dislodged	<ul style="list-style-type: none"> <li>❖ Transport promptly</li> </ul>

## Appendix C – Glossary

<p>Specialized terms are used in this session:</p> <p><b>abdomen-</b> the portion of the trunk between the chest and pelvis; the stomach region</p> <p><b>abdominal-</b> relating to the abdomen</p> <p><b>apnea-</b> absence or cessation of breathing for a period of seconds, followed by a decrease in heart rate</p> <p><b>aspirate, aspiration-</b> to inhale liquid or solid matter into the airways</p> <p><b>asthma-</b> a respiratory disease causing narrowing of the lower airway passages</p> <p><b>Broviac® catheter-</b> registered trademark of C.R.Bard, Inc. and its related company, BCR, Inc., is a type of catheter used for administering fluids or medications directly into a central vein, usually found in the chest region</p> <p><b>button-</b> another name for a percutaneous endoscopic gastrostomy (PEG)</p> <p><b>cannula-</b> a flexible tube</p> <p><b>catheter-</b> a flexible tube used for the passage of fluid</p> <p><b>central intravenous catheter-</b> a type of catheter used for administering fluids or medications directly into a central vein</p>	<p><b>cerebrospinal fluid (CSF)-</b> a fluid surrounding the brain and spinal cord</p> <p><b>colon-</b> part of the large intestine</p> <p><b>colostomy-</b> a surgical opening through the abdominal wall into the colon, with an external bag in place to receive digestive waste matter</p> <p><b>congenital-</b> existing at birth</p> <p><b>contraction-</b> sudden tightening of muscle</p> <p><b>CSF-</b> cerebrospinal fluid</p> <p><b>decannulation plug-</b> a plug located in the outer cannula of a fenestrated tracheostomy tube that blocks airflow through the stoma</p> <p><b>diaphragm-</b> a large, cup-shaped muscle located between the chest and abdomen that is used in breathing</p> <p><b>dislodge-</b> cause something to lose its proper position</p> <p><b>endoscope-</b> an instrument used to view the inside of a body cavity or hollow organ</p> <p><b>endotracheal-</b> within the windpipe</p> <p><b>esophagus-</b> a muscular tube within the throat that leads to the stomach, through which food and liquids are swallowed</p>
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**Hickman**®- registered trademark of C.R.Bard, Inc. and its related company, BCR, Inc., is a type of catheter used for administering fluids or medications directly into a central vein, usually found in the chest region

**home care provider**- an individual, usually trained in CPR and the use of certain medical equipment, who provides health care services in the home (may or may not be an RN)

**hypoperfusion**- another name for shock

**ileum**- part of the small intestine

**ileostomy**- a surgical opening through the abdominal wall into the ileum, with an external bag in place to receive digestive waste matter

**intravenous (IV)**- within the vein

**intubation**- to insert a tube into a body opening

**jejunal**- relating to the jejunum

**jejunostomy**- a surgical opening into the jejunum

**jejunostomy tube (JT)**- a tube that runs through the skin and into the small intestine, used for administering liquid nutrients or medications

**jejunum**- a portion of the small intestine

**listless**- lacking energy

**nasogastric**- relating to the nose and stomach

**nasogastric tube (NGT)**- a tube that runs through the nose and into the stomach, used for administering liquid nutrients or medications

**Nasojejunal**- relating to the nose and jejunum

**nasojejunal tube (NJT)**- a tube that runs through the nose and into the small intestine, used for administering liquid nutrients or medications

**neonatal**- relating to a newborn infant

**neurologic, neurological**- relating to the brain and nerves

**orogastric**- relating to the mouth and stomach

**orogastric tube (OGT)**- a tube that runs through the mouth and into the stomach, used for administering liquid nutrients or medications

**orojejunal**- relating to the mouth and jejunum

**orojejunal tube (OJT)**- a tube that runs through the mouth and into the small intestine, used for administering liquid nutrients or medications

**ostomy**- a surgical opening

**oxygenation**- to add oxygen

**percutaneous**- through the skin

<p><b>percutaneous endoscopic gastrostomy (PEG)- a capped tube that runs through the skin into the stomach, used for administering liquid nutrients or medications</b></p>	<p><b>tracheostomy tube- a tube that runs through the skin of the neck into the windpipe</b></p>
<p><b>perfusion- the flow of blood through the blood vessels and skin</b></p>	<p><b>ventilator- a device to assist breathing</b></p>
<p><b>premature- describes an infant born prior to 37 weeks gestation</b></p>	<p><b>verbal- relating to written or spoken words</b></p>
<p><b>seizure- an abnormal electrical discharge of the brain cells, often resulting in muscle contractions</b></p>	<p><b>vocal cords- fold of tissue located within the voice box that are used to produce sound</b></p>
<p><b>shock- the body's reaction when blood circulation fails; also called hypoperfusion</b></p>	
<p><b>shunt- a surgically inserted tube for draining fluid</b></p>	
<p><b>sign- assessment finding that indicates illness or injury</b></p>	
<p><b>spasticity- a medical condition that limits movement of the joints and muscles</b></p>	
<p><b>stoma- a surgical opening</b></p>	
<p><b>symptom- an indication of illness described by the patient or parent</b></p>	
<p><b>tendon- a band of tough fibrous tissue that connects muscle to bone</b></p>	
<p><b>tracheostomy- a surgical opening into the windpipe/trachea</b></p>	

## Appendix D: References

### Core

George L. Foltin, Michael G. Tunik, Arthur Cooper, David Markenson, Marsha Treiber, Regina Phillips, Tamia Karpeles. *Teaching Resource for Instructors in Prehospital Pediatrics*. New York, NY: Center for Pediatric Emergency Medicine, 1998.

Wiebe, Robert A., Barbara A. Barlow, Ronald A. Furnival, Barry W. Heath, Steven E. Drug, Karin A. McCloskey, Lee A. Pyles, Deborah Mulligan-Smith, Timothy S. Yeh. "Emergency Preparedness for Children with Special Health Care Needs." *Pediatrics* Vol 4 (1999): 1-6

Eichelberger, Martin R., Jane W. Ball, Geraldine L. Pratsch, and John R. Clark. *Pediatric Emergencies: A Manual for Prehospital Care Providers*. 2d ed. Upper Saddle River, NJ: Prentice Hall, 1998

➤ See "Medical Emergencies: Children Assisted by High-Technology Equipment," 131-132.

Zitelli, Basil J., Davis, Holly W. *Atlas of Pediatric Physical Diagnosis*. 3d ed. St. Louis, MO: Mosby-Year Book, Inc., 1997

Wong, Donna L., Rollins, Judy H., Whaley & Wong's *Essentials of Pediatric Nursing*. 4<sup>th</sup> ed. St. Louis, MO: Mosby-Year Book, Inc., 1993

Glasser, J., S. S. McInturiff, and C. Yuska. *Tracheostomy Tube: Adult Home Care Guide*. Shiley Tracheostomy Products (Sorin Biomedical), 1992.

Richardson, M., E. Student, D. O'Boyle, M. Smyth, and T. W. Wheeler. "Establishment of a State-Supported, Specialized Home Care Program for Children with Complex Health Care Needs." *Issues in Comprehensive Pediatric Nursing* 15:2 (1992): 93-122.

Rushton, Breck. "Child with Special Health-Care Needs." In *Prehospital Care of Pediatric Emergencies*, edited by J. S. Seidel and D. P. Henderson. Sudbury, MA: Jones & Bartlett, 1997. 150-159.

Wertz, E. M. "Special Needs Pediatric Patient." *Emergency Medical Services* 22:3 (1993): 40-49.

### EMSC Resources

Emergency Care Plans for Children with Special Health Care Needs Fact Sheet, EMSC National Resource Center, 111 Michigan Avenue, NW, Washington, DC 20010

**Non-EMSC Resources**

Traumatic Brain Injury Fact Sheet #18 (FS18), 1999. National Information Center for Children and Youth with Disabilities (NICHCY), PO Box 1492, Washington, DC 20013

General Information about Spina Bifida, Fact Sheet #12 (FS12), 1999. National Information Center for Children and Youth with Disabilities (NICHCY), PO Box 1492, Washington, DC, 20013

General Information about Severe and/or Multiple Disabilities, Fact Sheet #10 (FS10), 1999. National Information Center for Children and Youth with Disabilities (NICHCY), PO Box 1492, Washington, DC, 20013

General Information about Epilepsy, Fact Sheet #6 (FS6), 1999. National Information Center for Children and Youth with Disabilities, (NICHCY), PO Box 1492, Washington, DC, 20013