

Children with Special Health Care Needs

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Objectives



- ▶ Define children with special healthcare needs
- ▶ Discuss supplies, technology dependence, communication, and transportation
- ▶ Discuss different diagnosis which may be seen with children of special health care needs



Children are more vulnerable

- Skin is thinner and larger surface to mass ratio
- Inhale larger doses in same period of time
- Closer to the ground
- Less fluid reserve-dehydrates faster
- Limited motor and cognitive skills
- Can shift quickly from stable to life-threatening
- More sensitive to changes in temperature and environment



What type of conditions

- Respiratory
- Cardiac conditions
- Endocrine disorders
- Genetic Disorders
- Hematology and cancer disorders
- Immune disorders
- Kidney Disorders



Even More

- Metabolic disorders
- Severe food allergies
- Neurological disorders
- Developmental disorders
- Mental Health disorders
- annnddd.....



Special Health Care Needs

Special health care needs include any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs. The condition may be congenital, developmental, or acquired through disease, trauma, or environmental cause and may impose limitations in performing daily self-maintenance activities or substantial limitations in a major life activity. Health care for individuals with special needs requires specialized knowledge acquired by additional training, as well as increased awareness and attention, adaptation, and accommodative measures beyond what are considered routine.



Pediatric Prevalence

- ▶ Fourteen percent of children under age 18 in the U.S. have special health care needs.
- ▶ At least one CSHCN is present in 21.8% of households with children.
- ▶ Among preschool children (ages birth through five), just under eight percent have special health care needs.



Is there any commonalities?

- Baseline is difficult to assess
 - Care givers input is valuable
- Many require medical devices, supplies and treatments
- Many require medications
 - Insulin
 - Anti-epileptics
 - Inhalers
 - Etc.



And the list goes on

- Limited to no movement
- Exercise intolerance
- Require tubes or parenteral feedings
- Crisis may be exacerbated by separation
- Communication may be limited or non-existent
- Immunocompromised due to condition



Why Talk About This?

Mark is a 17-month-old boy born at 27 weeks gestational age. His postnatal course is significant for mechanical ventilation until he was 6 months of age. He was born with respiratory distress syndrome and now has bronchopulmonary dysplasia. Currently, Mark is mechanically ventilated only while asleep. He has a tracheostomy tube. He has a home health care nurse for 8 hours per day while his parents are at work, and his parents manage his equipment the other 16 hours per day.



Case Presentation



He has recently been weaned off diuretics and for the last two days his family has noted that he is producing more secretions through his tracheostomy tube than usual. Today he has a fever, and the home health care nurse has called 9-1-1 because of sudden onset of respiratory distress that she is unable to relieve. When EMS arrives at Mark's home, the home health care nurse meets them at the door. She directs them to the living room where Mark sleeps. Next to his bed are the ventilator and oxygen tank.

The nurse reports suctioning the tracheostomy tube several times and he is still in distress. EMS notes that Mark is breathing quickly and has marked retractions, pulse ox reads 85%.



Case Presentation

- ▶ What are the primary concerns of this child?
- ▶ What should the EMS providers do first?
- ▶ What are the possible problems with this child?



Pediatric Prevalence



- ▶ 31% of children have one or more chronic physical condition at some time during their youth
- ▶ 20% of children have developmental delays, behavioral and emotional problems, and/or learning disabilities
- ▶ 6% of children have severe chronic illness

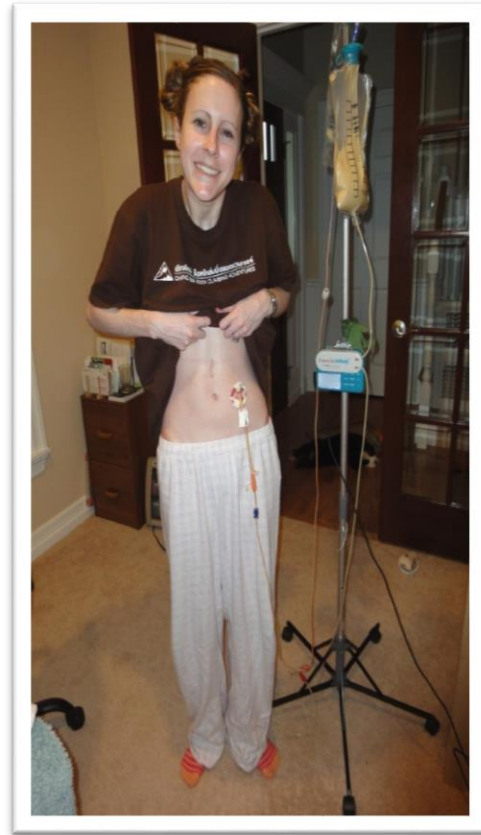


Medical Supplies 101



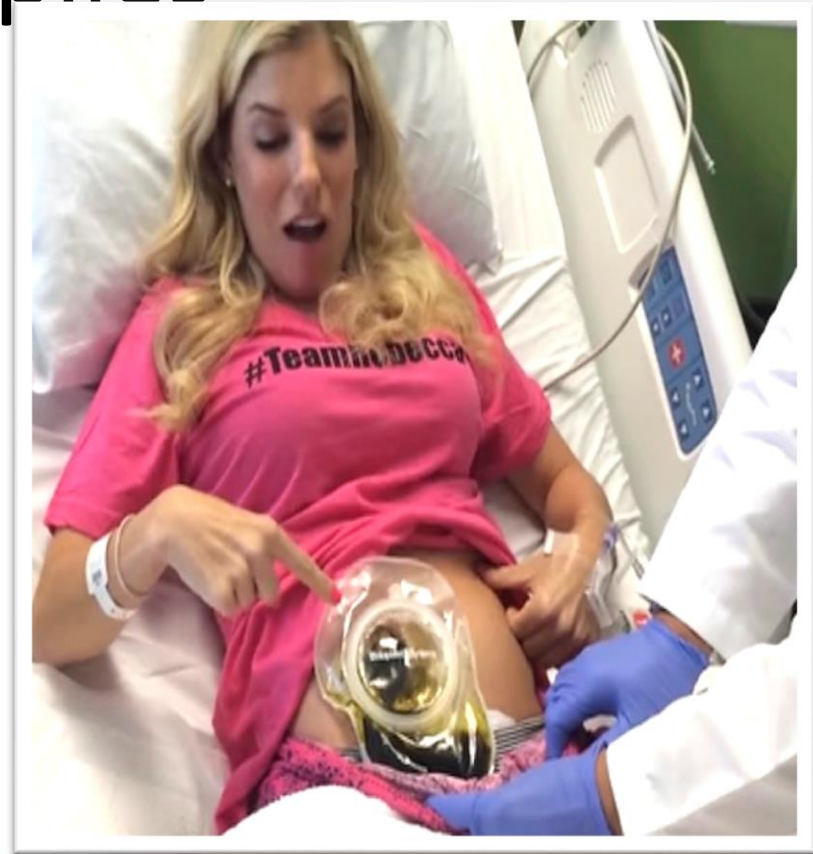
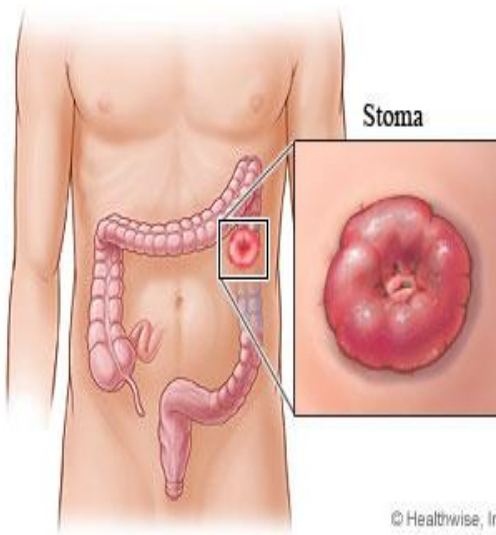
Medical Supplies

▶ Feeding tubes



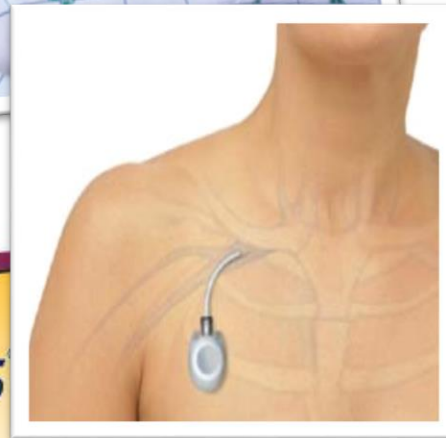
Medical Supplies

► Ostomies



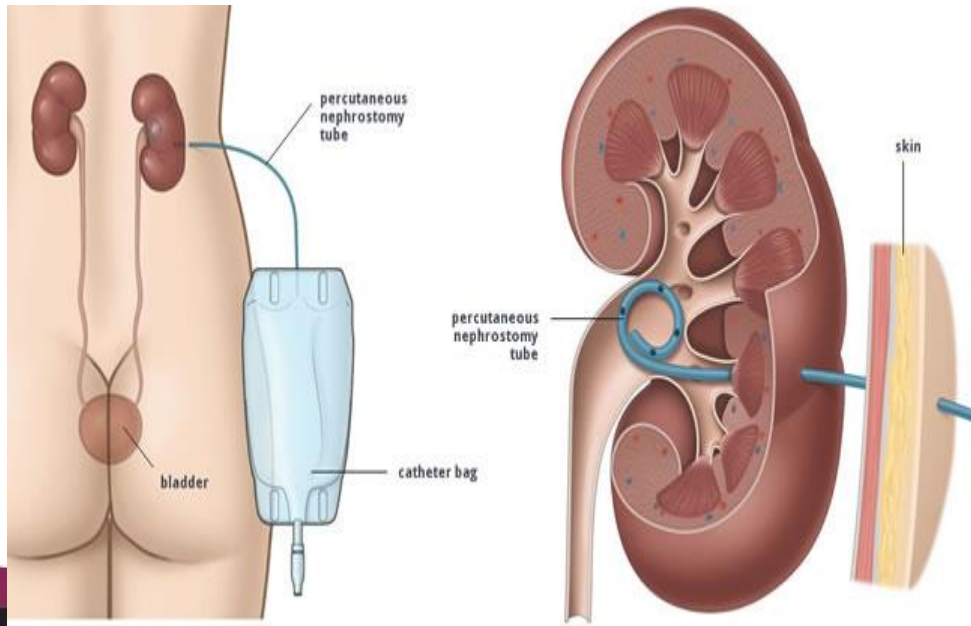
Medical Supplies

▶ Central lines



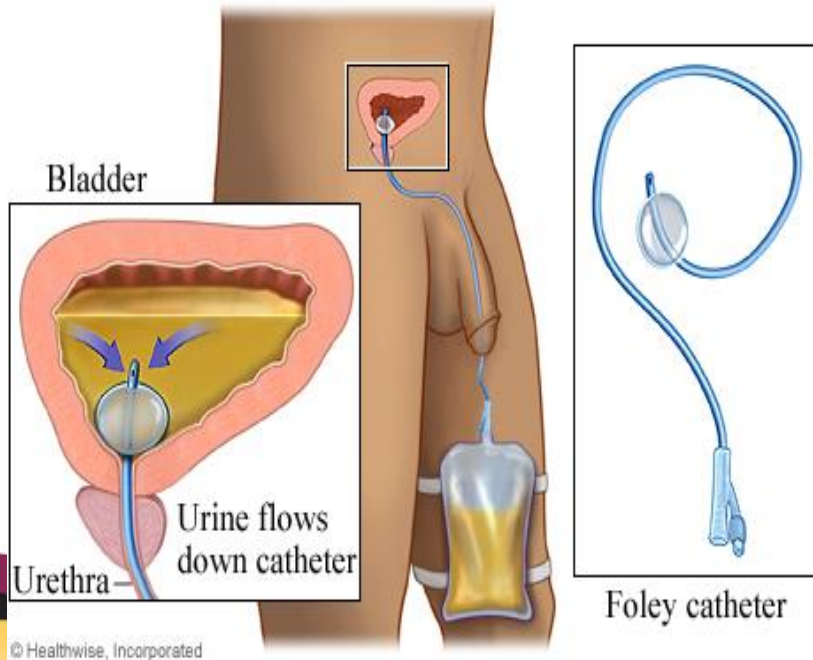
Medical Supplies

▶ Uretero/Nephrostomies



Medical Supplies

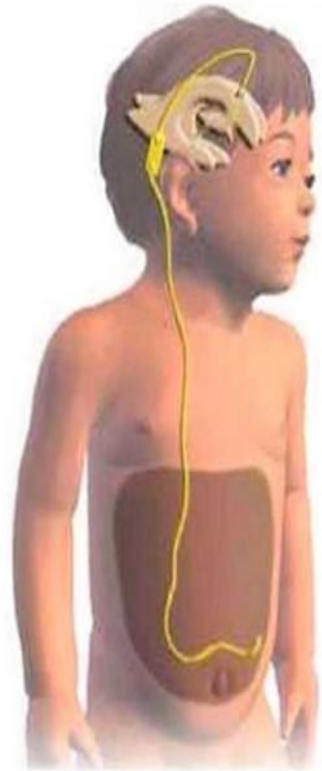
▶ Foley/Suprapubic catheter



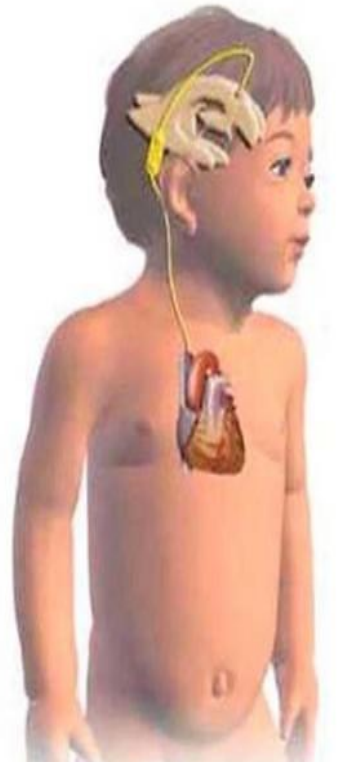
Medical Supplies

▶ CSF shunt

VP SHUNT

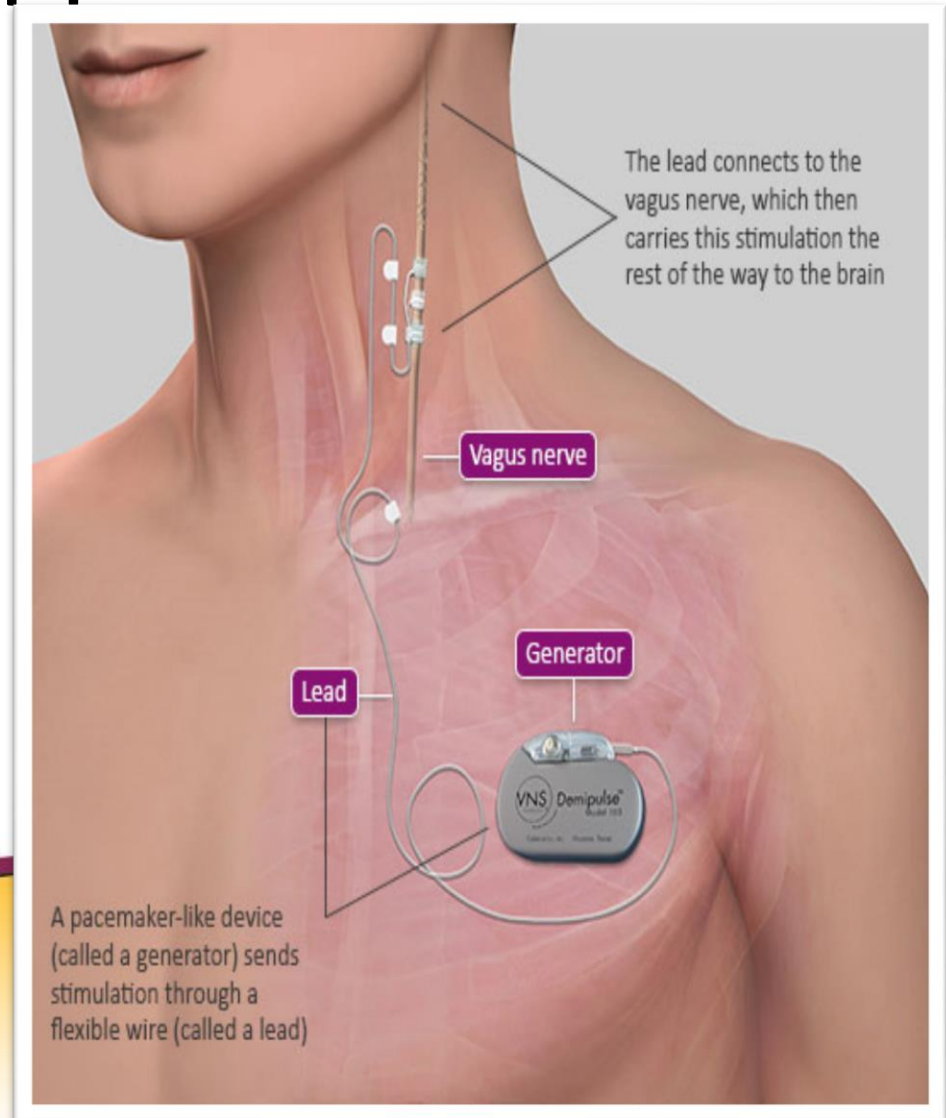
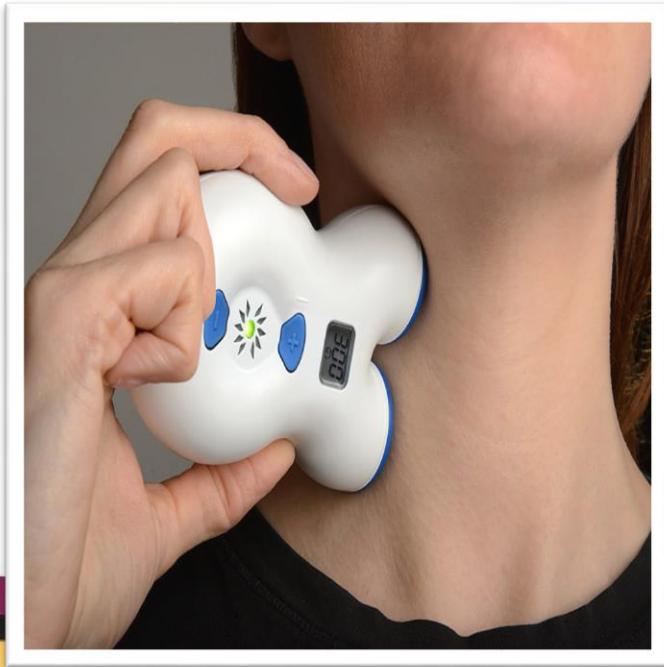


VA SHUNT



Medical Supplies

▶ Vagal nerve stimulator



Medical Equipment at home

▶ Ventilator



Home Supplies

▶ Suction



Food & Feeding Supplies

- ▶ Nasogastric
- ▶ Gastric
- ▶ Jejunal
- ▶ Formulas-kids, adults, dialysis patients
- ▶ NPO or supplemental
- ▶ Bolus or continuous



Mobility & Transport Issues

- ▶ Ambulate
- ▶ Walker/cane
- ▶ Escort/Assistant
- ▶ Wheelchair
- ▶ Stairs
- ▶ Is there room?
- ▶ Manpower



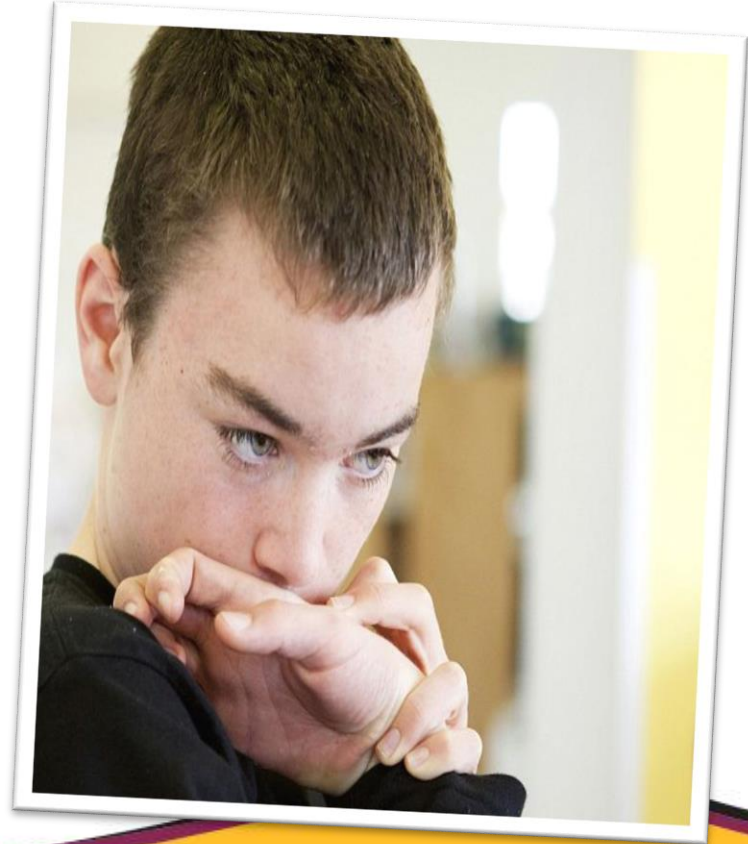
Technology Dependence

- ▶ Ventilator
- ▶ Suction
- ▶ Dialysis
- ▶ Pacemaker
- ▶ Implanted defibrillator
- ▶ Ventricular assist device
- ▶ Environmental control



Mental Health

- ▶ Stress & Anxiety
- ▶ Paranoia/schizophrenia
- ▶ PTSD
- ▶ Autism
- ▶ Separation
- ▶ Trauma
- ▶ Children



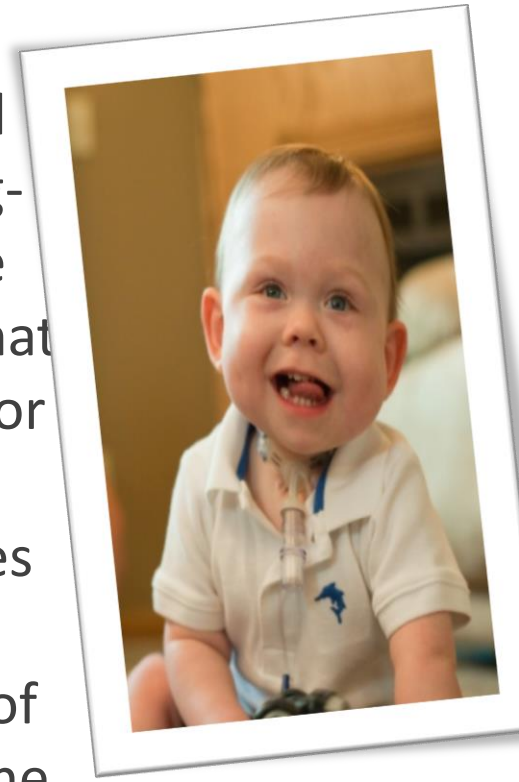
How to Support Families

- ▶ Listen carefully and learn
- ▶ Don't rush to judgment
- ▶ Be open minded
- ▶ Remember parents, siblings, children, partners, grandparents
- ▶ Recognize the importance of the caregiver input.



Case Progression

The primary concern is adequacy of the airway and breathing in this child. EMS attach their manual bag-ventilator to the boy's tracheostomy tube and note that bagging is difficult. The nurse and EMS decide that the tube may be obstructed, so the nurse prepares for a tracheostomy tube change. She opens a size 4.5 tracheostomy tube. She places ties through the holes in the wings of the tube. She then quickly places a towel roll under the child's shoulders. She asks one of the EMTs to cut the tracheostomy ties and pull out the tube while she inserts the new tube.



Case Progression

EMS then attaches the manual bag ventilator to the newly inserted tracheostomy tube and administers several breaths. The pulse oximeter rises and is now 95%. The nurse and EMS conclude that Mark did have a mucous plug in his tube, and they begin to prepare Mark for transport. Other concerns in this child include a respiratory infection or an exacerbation of his bronchopulmonary dysplasia. This child has low respiratory reserve, so seemingly minor infections or asthma-like attacks can be life-threatening. The parents are notified and will meet the crew at the child's home hospital.



Key Points

- ▶ **LISTEN** to the pt & caregivers. They know their situation best. **INQUIRE** about: baseline abilities, syndromes/diseases, what is different, symptoms, devices/medications, usual vital signs.
- ▶ Assess and communicate directly with the pt based on developmental age, not chronological age. **DO NOT** make assumptions about their level of understanding based on their appearance.



Key Points

- ▶ Look for MedicAlert® jewelry or health forms, if usual caregiver is not available.
- ▶ **Bring necessary specialized equipment and medications** with the pt if possible (ventilator, tracheostomy tube or gastrostomy tube, etc.)
- ▶ Ask what the best way to move the pt is, particularly if the pt is prone to fractures. If pt has a brace or splint on an affected area, leave the brace or splint on & immobilize around it.





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