

This presentation was designed for Health Home Care Coordinators for the Washington State Integration Project with The Health Care Authority and The Department of Social and Health Services. It was presented as a live webinar by Dr. Lily Koblenz, MD on December 11, 2014.

This topic is not required and provides Care Coordinators with information about children and chronic conditions care coordinators may encounter when working with children and families. It provide information about home health needs and types of feeding and durable medical equipment used to maintain children in their own homes.





# Pediatric Home Health Care-Background- Who and Why?



- -Tremendous advances in neonatal, medical and surgical care of infants and children have led to survival of an increased number of Children with Special Health Care Needs (CSHCN).
- -Increased emphasis on caring for CSHCN at home, rather than in the hospital.

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## **Rationale for Home Health Care Goals of Home Health Care**

#### Rationale

- Improved psychological health and development of the child
- Improved family function
- Decreased cost compared with hospitalization
- Improvements in technology have facilitated care at home

#### Goals

- Optimize health and function of child and family
- Minimize recurrent or prolonged hospitalizations

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# **CSHCN**

#### CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- Definition
  - Children who have, or are at risk of having, a chronic physical, developmental, behavioral or emotional condition and who require health and related services of a type or amount beyond that required by children generally.
  - >10 million children in the US meet this definition.

# Subset of CSHCN are Medically Complex

- Substantial health care needs
- More than one chronic condition
- Technology dependent
- Severe neurodevelopmental impairment

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## DIAGNOSES COMMON TO MEDICALLY COMPLEX CSHCN

- · Numerous diagnoses but certain categories predominate:
  - Preterm birth
  - Congenital genetic and metabolic disorders
  - Neurologic and Neuromuscular disorders
  - Sequelae of severe infection
  - Sequelae of severe injury
  - Malignancy

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### **TECHNOLOGY DEPENDENT:**

Use of medical devices which are necessary to prevent adverse health consequences and/or hospitalization.

- Common examples of technology seen in home care:
  - Oxygen
  - Mechanical ventilators
  - CPAP or BiPAP machines.
  - Suction machines
  - Indwelling IV catheters
  - Enteral feeding tubes and pumps
  - Colostomy bags
  - Urinary catheters
  - Specialized mobility and seating devices

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# Examples of situations in which one would encounter use of technology in children at home:

- Osteomyelitis (infection of bone)
  - Indwelling IV catheter used to administer a prolonged course of antibiotics at home
- · Respiratory Failure
  - Use of home ventilator and oxygen
- Upper Airway Obstruction
  - Tracheostomy and CPAP or BiPAP and oxygen
- · Inadequate Oral Feedings
  - Nasogastric or Gastrostomy tube feedings
- Short Gut Syndrome
  - Total Parenteral Nutrition administered through indwelling IV catheter







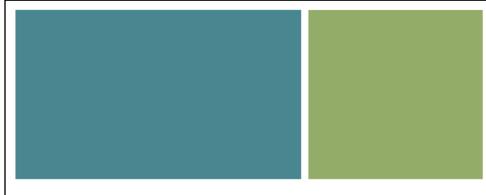
# Planning for discharge from hospital to home care. Things to consider/ plan for:

- · Assessment of family and home
- Identification of Primary Care Provider (PCP)
- Training of home-caregivers
- Arrange home care nursing (in some cases)
- Arrange for educational/ developmental services
- · Arrange for durable medical equipment
- · Deal with insurance coverage issues









## **COMMON SCENARIOS LEADING** TO PEDIATRIC HOME CARE



LIST OF POTENTIAL DIAGNOSES IS EXTENSIVE. MOST CHILDREN DO NOT HAVE JUST ONE DISORDER. TYPICALLY THEY HAVE MULTIPLE DISORDERS OR THEY HAVE A DISORDER THAT IS SO OVERWHELMING THAT IT CAUSES MULTIPLE ORGANS TO FAIL OR MALFUNCTION, THUS CREATING SECONDARY DISEASES.





# **EXAMPLE- CASE #1-**13 year old female with history of non-accidental trauma in infancy

- Primary insult: Severe brain injury
- Direct consequences of primary insult: Poor brain growth, global developmental delay, seizure disorder
- Subsequent consequences:
  - GI- Dysphagia (swallowing problems), Gastrostomy tube dependence, GERD (reflux), Constipation
  - **Respiratory-** Poor control of secretions, Recurrent aspiration pneumonia, Upper airway obstruction, Chronic lung disease
  - Neuromuscular- Spasticity, Muscle contractures
  - Skeletal- Scoliosis, Hip dislocation, Osteopenia, Fractures
  - CV- Poor peripheral circulation
  - Skin- Decubitus ulcers

(continued next slide)







#### **EXAMPLE- CASE #1-**

## 13 year old female with history of non-accidental trauma in infancy (continued)

- Subsequent consequences continued:
  - Vision- Cortical blindness
  - Hearing- Neurosensory hearing loss
  - Urinary- Incontinence, Incomplete bladder emptying, Recurrent urinary tract infections
  - Pain- Various etiologies related to all of the above, often not easy to identify the source
- Technologies- GTT, feeding pump, suction machine, BiPAP machine, Oxygen, Nebulizer, Circumferential chest vest, Baclofen pump, Hoyer lift, hospital bed, wheelchair, stander, bath seat, car seat, incontinence supplies







# **EXAMPLE- CASE #1-**13 year old female with history of non-accidental trauma in infancy (continued)

- Medical providers involved: PCP, Gastroenterologist, Pulmonologist, ENT, Neurologist, Physiatrist (Rehab), Orthopedic Surg, Physical therapist, Occupational therapist, +/- Opthalmologist/ Audiologist/ General Surg./Urology/ Nephrology
- Services required: Durable medical equip provider, Medical supplies provider, Respiratory equip. provider
- Education: IEP plan, Special education classroom, Special education bus service, Specific therapies at school.
- Home health services: Medicaid personal care assistant, No provision for home health nursing in most cases.







## **EXAMPLE- CASE #2-**5 month old male infant, born at 24 weeks gestational age

- **Primary insult:** Extreme prematurity
- Direct consequences of the primary insult: Respiratory Distress Syndrome, Necrotizing Enterocolitis, Intraventricular hemorrhage
- Subsequent consequences:
  - Respiratory- Chronic lung disease of prematurity (BPD), +/- home ventilation, +/- home oxygen
  - ENT- subglottic stenosis (narrowing of the airway related to prolonged intubation), tracheostomy
  - GI- short gut syndrome (surgical removal of necrotic bowel), +/colostomy/ ileostomy , Dysphagia/ GTT dependence, GERD, +/-Nissen fundoplication, +/- Parenteral nutrition with central catheter







# **EXAMPLE- CASE #2-**5 month old male infant, born at 24 weeks gestational age (continued)

- · Subsequent consequences (continued)-
  - **Neurologic-** Periventricular leukomalacia, Cerebral palsy, Muscle contractures, Spasticity, Developmental delays
  - Vision- Retinopathy of prematurity
  - Infectious disease- risk of sepsis because of central venous catheter, risk of severe RSV disease
  - **Hearing-** increased risk of sensori-neural hearing impairment
- **Technologies-** Home ventilator, Oxygen, Pulse oximeter/ other monitors, Suction machine, Feeding pump, IV medication pump, Medical stroller
- Medical Providers- PCP, Pulmonologist, GI, Nutrition, Neurologist, Therapists (PT/OT/ST), General surg., Opthal, +/- Develop. Pediatrician, Audiologist, Physiatrist (rehab)







# **EXAMPLE- CASE #2-**5 month old male infant, born at 24 weeks gestational age (continued)

- Services required: Home nursing (at least 8 hours per day so parents can sleep), Respiratory equipment supplier, Durable medical equipment supplier, Medical supply provider, Pharmacy (specialized for TPN)
- Education: Birth to three enrollment- Family resource coordinator (FRC), home teacher, therapists, +/- early learning center







## LISTING OF COMMON SCENARIOS THAT LEAD TO THE NEED FOR PEDIATRIC HOME CARE

#### Overwhelming Neurodevelopmental Impairment:

- Hypoxic-ischemic encephalopathy, Near-drowning, Severe brain injury (accidental or non-accidental), Overwhelming infection, Genetic abnormality causing abnormal brain development.

## Premature infant with extensive sequelae:

- Chronic lung disease, Subglottic stenosis with tracheostomy dependence
- Necrotizing enterocolitis with short gut syndrome
- Intraventricular hemorrhage with development of Cerebral Palsy
- Neonatal apnea/ bradycardia

#### Respiratory disorders:

 Cystic fibrosis, Central hypoventilation, Severe asthma, other chronic lung diseases







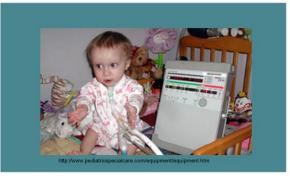
# LISTING OF COMMON SCENARIOS THAT LEAD TO THE NEED FOR PEDIATRIC HOME CARE (continued)

- Spinal Cord injury
- Renal failure
- Malignancy
- · Congenital heart disease
- · Gastrointestinal disorders
  - Malabsorption, Severe GERD, Severe Constipation, Liver disease
- Hematologic disorders
  - Sickle Cell disease, Thalassemia, Hemophilia and other clotting disorders, Disorders associated with increased clotting
- Endocrine disorders
  - Diabetes Mellitus, Hypopituitarism









#### RESPIRATORY CARE ISSUES



IMPROVED SURVIVAL OF CHILDREN WITH CHRONIC PULMONARY AND NEUROMUSCULAR ILLNESS HAS LED TO INCREASED NEED FOR CHRONIC HOME VENTILATION.

HOME CARE OPTIMIZES HEALTH, PSYCHOSOCIAL DEVELOPMENT AND FAMILY WELL-BEING AND IS LESS EXPENSIVE.



## CONSIDERATIONS WHEN CHOOSING TO PURSUE HOME **VENTILATION:**

- Children with chronic lung disease: may see improvement in pulmonary function over time with lung growth and repair.
- Children with progressive neuromuscular disease: will eventually progress to respiratory failure. Ventilation prolongs life and may improve life. Family and child should always have the option to discontinue support if the progressive neuromuscular disorder becomes intolerable to the child.
- Children with terminal illness: goal is to decrease suffering and allow the child to die in relative comfort of home.
- Children with severe brain injury and persistent vegetative **state:** with no hope of improvement or recovery, careful consideration needs to be given to the decision to ventilate.
- Children who benefit from nocturnal ventilation: examples include- children being weaned from ventilation, early stage neuromuscular disease, central hypoventilation syndromes (can willfully breathe when awake/ alert)

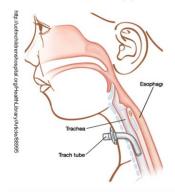






# TRACHEOSTOMY

- **REASONS FOR TRACHEOSTOMY:** 
  - Need for long-term ventilatory support
  - Neurologic dysfunction causing a floppy airway or inability to clear secretions
  - Abnormal upper airway anatomy











#### RISKS and CONCERNS RELATED TO TRACHEOSTOMY-

- Trachea usually humidifies the air and filters secretions from the airway. This role is disrupted by placement of trach. tube.
- Thick secretions can form and mucous can plug the tube.
- Pressure of the trach tube and suction catheters can irritate and damage the lining of the trachea.
- Overinflated tracheal cuffs can cause necrosis/ scarring/ stenosis of the trachea.
- Significant training of caregivers required.
- Families generally require home-nursing services at least at night so that they can sleep.
- · Child will need nurse or trained caregiver (one-on-one) to accompany him/her to school or developmental programming.







#### **HOME OXYGEN THERAPY**

Oxygen therapy is one of the most common services in pediatric home care. In the past, patients were hospitalized for prolonged periods of time just so that they could receive oxygen. Home oxygen is usually safe, cost-effective and improves quality of life for patient and family.

#### COMMON REASONS FOR O2 THERAPY:

- Bronchopulmonary Dysplasia (chronic lung disease of prematurity)
- Cystic fibrosis
- Other chronic lung diseases
- Neurologic/ neuromuscular causes

#### OXYGEN DELIVERY DEVICES:

- Nasal cannula is the most frequent low-flow O2 delivery device
- Tracheostomy patients receive O2 through their trach.
- Oxygen can be given via ventilator or CPAP/ BiPAP machine
- VARIETY OF FORMS OF OXYGEN FOR HOME USE







## **VENTILATION TYPES**

- Portable Positive Pressure Ventilation via Tracheostomy
  - Provides ventilation at a set rate to patients via their tracheostomy
  - Requires electricity but capable of battery operation for at least 1 hour

http://www.pediatrichomes ervice.com/blog/tag/travel-with-medically-fragille-kids











## NONINVASIVE POSITIVE PRESSURE VENTILATION **CPAP- Continuous Positive Pressure Ventilation BiPAP- Bi-level Positive Pressure Ventilation**

- Positive pressure via nasal or face mask or tracheostomy
- Either one level of pressure (CPAP) or a different flow rate set for inspiration and expiration (BiPAP)
- · Often used only at night and during naps





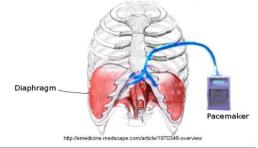






## DIAPHRAGMATIC PACING

- · Used for children who have a high spinal cord injury or abnormalities of central (brain-based) control of respiration.
- · Uses the diaphragm as a respiratory pump.
- Surgically implanted electrodes stimulate the phrenic nerve.
- · Stimulation of the phrenic nerve causes the diaphragm to contract and expand the lungs which draws air into them.









#### OTHER RESPIRATORY CARE TECHNOLOGIES

- Pulse oximeter devices- measure oxygen saturation and heart rate
- Suction equipment
- Aerosol therapy- home nebulizer machines
- · Airway clearance devices:
  - Mechanical vibrators used for chest percussion
  - Circumferential chest vests
  - Cough assist devices











# THE FULLY-LOADED, VENTILATED CHILD, IN HER MEDICAL STROLLER

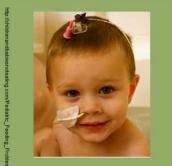


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# FEEDING ISSUES IN PEDIATRIC HOME CARE



Oral feeding is the best and most normal means of feeding and should be the goal whenever it is safe and effective to meet nutritional needs.

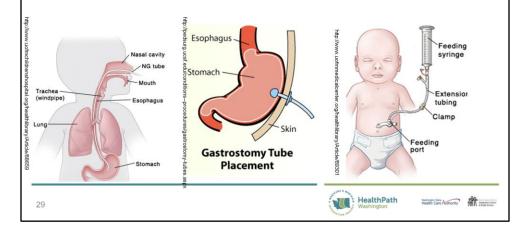
When oral feeding is not possible, other forms of GI (enteral) feeding are possible at home.

When the GI tract is not function, IV (parenteral) feeds are possible.

#### **ENTERAL FEEDS**

Used for children who are unable to adequately meet their nutritional needs orally but have adequate intestinal absorption and gut function.

- Feeding given directly into the stomach (gastric feed):
  - · Nasogastric (NG) feed- generally for short term use
  - · Gastrostomy (GTT) feed- need for long term enteral feeding

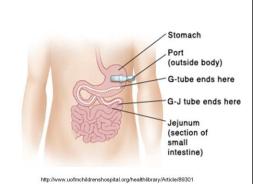


## **ENTERAL FEEDS**

Used for children who are unable to adequately meet their nutritional needs orally but have adequate intestinal absorption and gut function. (continued)

· Jejunal feeds are used when the stomach needs to be bypassed. NJ (nasojejunal) or GJT (Gastrojejunal) tubes





http://withineachheart.blogspot.com/2012\_02\_01\_archive.html







#### **CONSIDERATIONS IN ENTERAL FEEDING**

- Need to meet the nutritional and fluid needs of the patient.
- Premature infants, term infants, toddlers, and older children all have different nutritional needs. A nutritionist is often involved in supervising diet and supplements.
- Adequacy of feeding is monitored with frequent weight/ growth checks and periodic lab work.
- Children who are fed exclusively enterally will develop abnormalities in oral- motor development: "oral aversion". They will require feeding therapy (OT/ST).
- · Decision about how to administer enteral feeds is often partially dependant on the presence or absence of GERD (reflux).







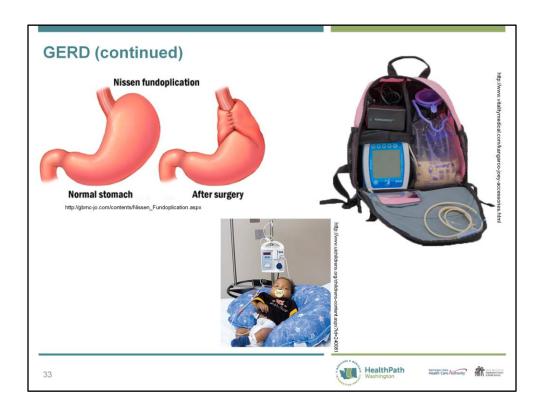
#### GASTROESOPHAGEAL REFLUX DISEASE- GERD

- GERD causes significant problems in children with chronic illness.
  - Pain and irritability from gastric acid burning the esophagus
  - Erosive esophagitis
  - Risk of aspiration of gastric contents into the lungs
  - Risk of gastric contents irritation the larynx and causing obstruction or triggering asthma
  - Poor weight gain because unable to tolerate full volume of feeds
- · Feeding options if GERD present:
  - Slow continuous feeds into the stomach (pump feeds)
  - Surgical treatment: Nissen Fundoplication
  - Jejunal feeds NJ or GJ slow continuous feeds to bypass the stomach









#### TOTAL PARENTERAL NUTRITION- TPN

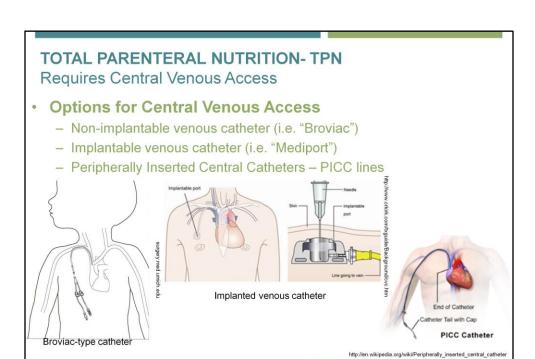
Meeting nutritional needs via intravenous feedings.

- Common reason for TPN: Short Gut Syndrome- removal of a large portion of the intestinal tract due to some severe injury or malformation of the intestine.
- Majority of patients should receive at least some portion of their feedings enterally, even if the majority of calories are coming from TPN.
- Nutritionist and Gastroenterologists usually work together to devise the exact contents of the TPN feed.
- Frequent laboratory measurements required.
- Complications can be very serious: Sepsis, Metabolic derangements, Cholestatic liver disease
- Least favorable and most potentially dangerous means of providing nutrition for extended periods of time.









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# OTHER ISSUES FREQUENTLY **ENCOUNTERED IN HOME CARE**



We are almost done!! Just a few more things to cover, hang in there, please!!

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# COMPLICATIONS OF IMMOBILITY

· Decubitus ulcers secondary to pressure, bony prominences, excessive thinness, poor peripheral circulation.



· Osteopenia and increased risk of fracture related to lack of weight-bearing, immobility, medications, nutritional deficiencies.

· Contractures related to spasticity.



• Elimination disorders: constipation, fecal impaction, bladder dysfunction, urinary retention, recurrent urinary tract infections







# **PAIN**

- Chronic pain- related to known disease process
- Intermittent unexpected pain- challenging to identify the source because of communication impairments.
- · Some possible sources of pain:
  - Ear infections
  - Urinary tract infections
  - Fecal impaction
  - Excessive gas
  - Dental disease
  - Fracture
  - Pancreatitis
  - Gall Bladder disease
  - Skin ulceration

etc... (many more possibilities)







# ASSISTIVE TECHNOLOGY IN THE HOME CARE SETTING

- POSITIONING DEVICES- equipment used to promote optimal posture and alignment in children who have not achieved head or trunk control
  - Positioning chairs- offers an alternative seating arrangement at home (beyond the wheelchair or medical stroller).
  - Pillows/ wedges/ inserts- assists with positioning in chair or bed.









http://www.bellabambinostore.com/out-stander-multi-positioning-stander.aspx







# ASSISTIVE TECHNOLOGY IN HOME CARE

# MOBILITY DEVICES

- Manual wheelchairs- used for children with sufficient upper body strength to propel themselves or in cases where patient lacks cognitive capacity to control a power wheelchair.
- Power wheelchairs- used for children with the cognitive ability to control their movement.
- Medical strollers- used for young children who are unable to propel themselves b/o severe cognitive, behavioral, or medical impairment.







www.1899wheelchair.com







# ASSISTIVE TECHNOLOGY IN HOME CARE

- ACTIVITIES OF DAILY LIVING DEVICES
  - Bath chairs, Shower chairs, Inflatable bathtubs
  - Specialized potty chairs/ toilet seats
  - Car seats







www.rifton.com







### **DEVELOPMENTAL CONSIDERATIONS**

- MEDICALLY COMPLEX CHILDREN HAVE PARTICULAR EDUCATIONAL AND DEVELOPMENTAL NEEDS.
- BIRTH TO 3 SERVICES- Provide home teacher, family support, home-based therapies, vision/ hearing specific therapies.
- OVER 3 YEARS OF AGE- Local public school system will take over and provide developmental preschool until enrollment in kindergarten. Therapies at school. Transportation to and from school.
- OTHER SERVICES-
  - Early referral to evaluate for hearing/ vision deficits
  - Use of Physiatrists (Rehab specialists)
  - Use of Developmental pediatricians
  - Use of Developmental optometrists
  - Private/ community-based therapies (PT/ OT/ ST)
  - Infant/ Child/ Adolescent mental health providers







# **PRIMARY CARE** – Role of the Primary Care Provider (PCP)

- · PCP's play and important role in coordinating and managing the care of medically complex children.
  - Even children who are being followed by multiple specialists need to be seen at regular intervals by their PCP's.
  - They need longer clinic visits to address: acute concerns, chronic issues, health care maintenance (well child care), vaccinations.
  - They need to maintain detailed lists of chronic medical problems, medications, specialists, equipment providers, home care companies.
  - They need to have access to social workers, nutritionists, palliative care consultants and DENTISTS.











# PEDIATRIC HOME CARE



WORKING TO IMPROVE THE LIVES OF CHILDREN WITH COMPLEX MEDICAL NEEDS AND SUPPORTING FAMILIES AND CAREGIVERS SO THEY CAN BEST ENJOY THEIR TIME TOGETHER.





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### **EDUCATIONAL WEB-LINKS**

### **Tracheostomy and Ventilator education**

University of Wisconsin Pediatric Pulmonary Center. Pediatric Tracheostomy & Ventilator Care (Educational Resource, Self- Study Module). Retrieved November 18,2014 from http://www.uwppc.org/educational-resources/self-study-modules/pediatric-tracheostomyventilator-care/trach/index.html

Cincinnati Children's Hospital Medical Center- Center for Infants and Children with Special Needs. Care of the Child with a Tracheostomy (PDF). November 2009. Retrieved from www.cincinnatichildrens.org/assets/0/78/1067/1395/1957/1959/1961/...

## **Gastrostomy Tube Feeding**

Children's Hospitals and Clinics of Minnesota. A Guide for Parents of G-tube Care at Home (PDF). Retrieved November 8,201014 from www.childrensmn.org/manuals/pfs/homecare/196854.pdf







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