Health Home Care Coordinators Training

Pediatric Chronic Conditions and the PSC-17

April 12, 2018

Today's Presenter

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  - Home and Community Services Division
  - Aging and Long Term Support Administration
  - Washington State Department of Social and Health Services

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Objectives

- Present information about chronic conditions for children
  - Types of support needed (medical and home care)
- Review the Pediatric Symptom Checklist (PSC) – 17 and FLACC Behavioral Pain Assessment
- Provide Health Promotion: importance of immunizations
- Examine helpful resources for your clients and you

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

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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Common Scenarios Leading to Pediatric Home Care

- List of potential diagnoses is extensive
- Most children do not have just one disorder
- Typically they have more than one disorder or a single disorder that is so overwhelming that is causes multiple organs to malfunction or fail, creating secondary diseases

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Common Scenarios Leading to the Need for Pediatric Home Care (cont.)

- **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

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Common Scenarios Leading to the Need for Pediatric Home Care (cont.)

- **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

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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 and Goals for 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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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

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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

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Planning for discharge from hospital to home care: (cont.)

- Things to consider/ plan for:
  - Arrange home care nursing (in some cases)
  - Arrange for educational/ developmental services
  - Arrange for durable medical equipment
  - Deal with insurance coverage issues

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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

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Example- (cont.)

13 year old female with history of non-accidental trauma in infancy

- **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

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Example- (cont.)

13 year old female with history of non-accidental trauma in infancy

- **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.

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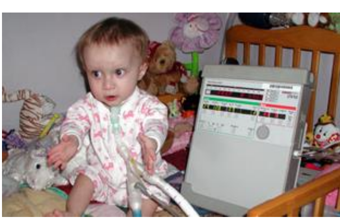
Respiratory Care Issues



http://www.pediatricspecialcare.com/equipment/equipment.htm

- 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.

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Which Children Go Home on a Ventilator:

- **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.
- **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)

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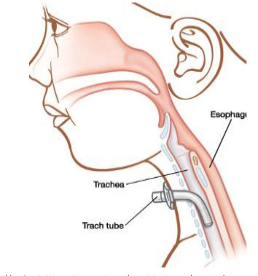
Tracheostomy

- **Reasons for tracheostomy:**
  - Need for long-term ventilator support
  - Neurologic dysfunction causing a floppy airway or inability to clear secretions
  - Abnormal upper airway anatomy



http://uofmchildrenshospital.org/HealthLibrary/Article/88995

http://www.enttx.com/airway-2/home-tracheotomy-care-instructions

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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.

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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

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Home Oxygen Therapy (cont.)

- **Common reasons for O2 Therapy:**
  - Bronchopulmonary Dysplasia (chronic lung disease of prematurity)
  - Cystic fibrosis
  - Other chronic lung diseases
  - Neurologic/ neuromuscular causes
- **Oxygen delivery services:**
  - 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 therapy for home use**

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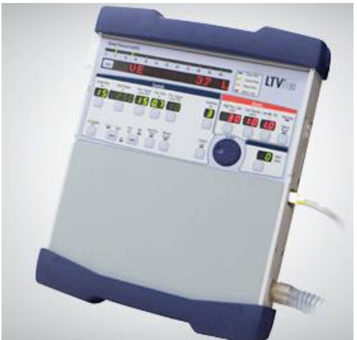
Ventilation Types

- **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.pediatrichomeservice.com/blog/tag/travel-with-medically-fragile-kids



http://www.carefusion.com/medical-products/respiratory/ventilation/ltv-series/ltv-1150.aspx

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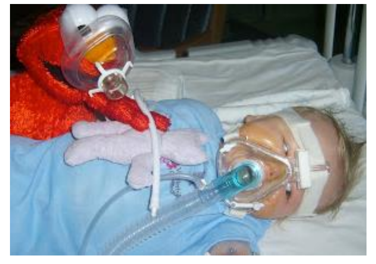
Noninvasive Positive Pressure Ventilation

- 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

sleepapneadisorder.info

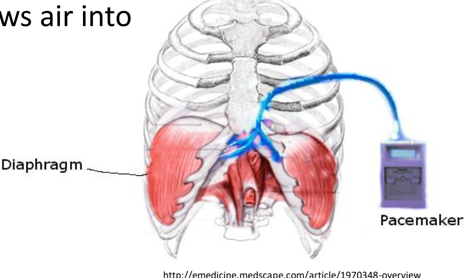


http://www.miracleformary.com/2007_12_01_archive.html

25

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.



http://emedicine.medscape.com/article/1970348-overview

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Other Respiratory 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

aleh.org

http://www.tracheostomy.com/faq/equipment/the_vest.htm

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The Fully-Loaded, Ventilated Child in Her Medical Stroller

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http://lovestellan.com/the-g-tube-a-christmas-story/

http://childrenandbabiesnoteating.com/Pediatric_Feeding_Problems.html

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.

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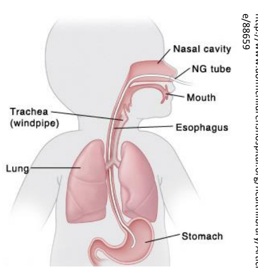
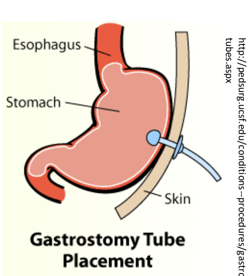
Enteral Feeds

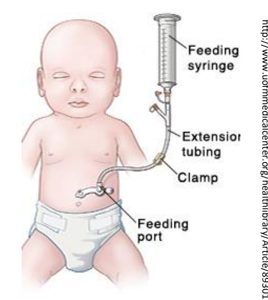
- Used for children who are unable to adequately meet their nutritional needs orally but have adequate intestinal absorption and gut function
- Feeding given directly into the stomach (gastric feed):
  - Nasogastric (NG) feed- generally for short term use
  - Gastrostomy (GTT) feed- need for long term enteral feeding



http://www.uofmchildrenshospital.org/healthlibrary/Article/88659



http://pedsurg.ucsf.edu/conditions--procedures/gastrostomy-tubes.aspx



http://www.uofmmedicalcenter.org/healthlibrary/Article/89301

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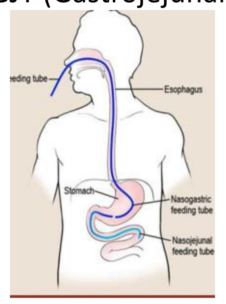
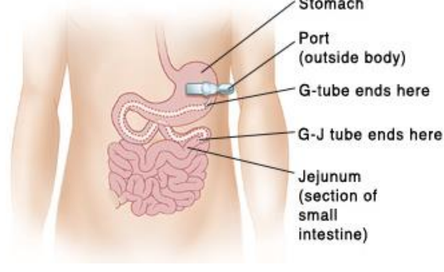
Enteral Feeds (cont.)

- 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



http://www.uofmchildrenshospital.org/healthlibrary/Article/89301

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Considerations in Enteral Feeds

- 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).

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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

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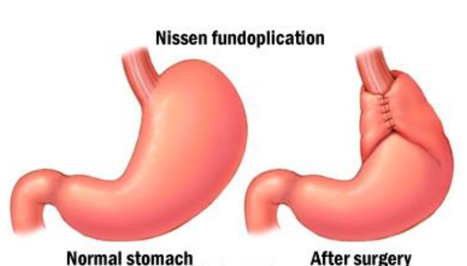
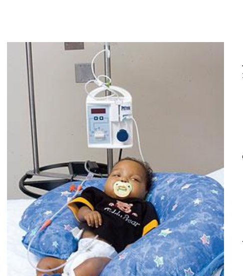
GERD (cont.)



http://gbmc-jo.com/contents/Nissen_Fundoplication.aspx



http://www.uichildrens.org/childrens-content.aspx?id=240081

http://www.vitalitymedical.com/kangaroo-joey-accessories.html

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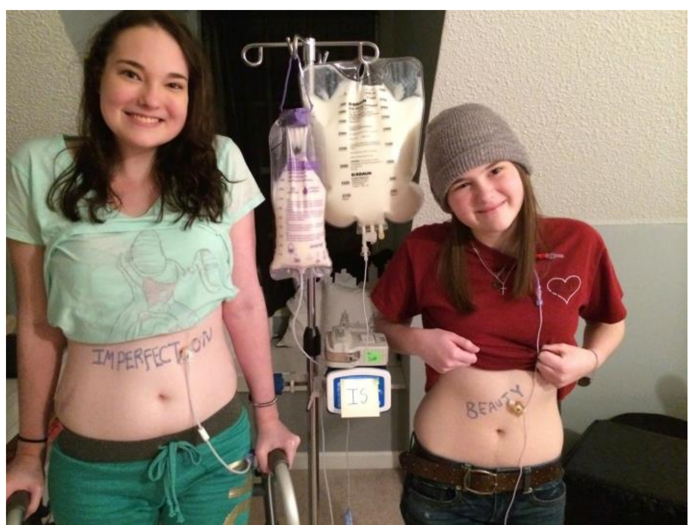
Two older girls receiving enteral feeds:



http://chronicallyawesome23.blogspot.com/2014/06/national-iv-drug-shortages.html

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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 Gastroenterologist 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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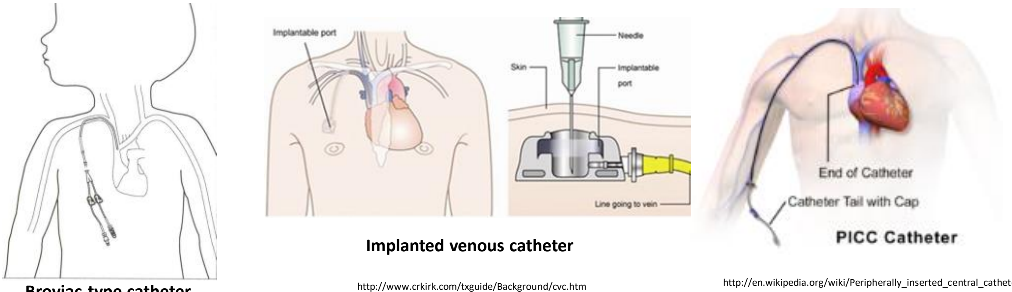
Total Parenteral Nutrition- TPN (cont.)

- **Require Central Venous Access**
- **Options for Central Venous Access**
  - Non-implantable venous catheter (i.e. “Broviac”)
  - Implantable venous catheter (i.e. “Mediport”)
  - Peripherally Inserted Central Catheters – PICC lines



Broviac-type catheter

Implanted venous catheter

http://www.crkirk.com/txguide/Background/cvc.htm

http://en.wikipedia.org/wiki/Peripherally_inserted_central_catheter

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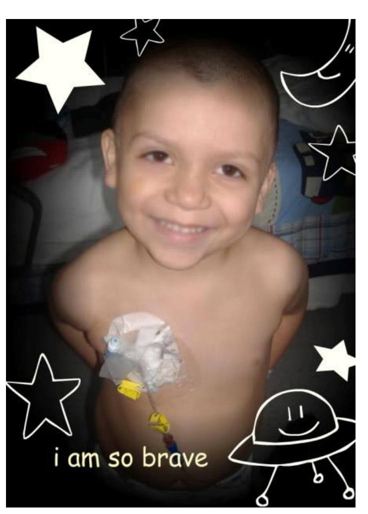
Central Venous Access for TPN

http://www.patrickhoopes.com/?tag=broviac-line&paged=2



innovateus.net

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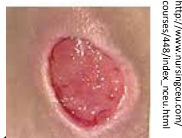
Complications of Immobility

- **Decubitus ulcers** secondary to pressure, bony prominences, excessive thinness, poor peripheral circulation



http://www.nursingceu.com/courses/448/index_nceu.html

- **Osteopenia (weak bones)** and increased risk of fracture related to lack of weight-bearing, immobility, medications, nutritional deficiencies

ht/tp://epichealthservices.com/osteopenia-need-know

- **Contractures** related to spasticity

http://www.mediclinic.ae/PageContent.aspx?pageId=795&groupId=26

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

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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)

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FLACC Behavioral Pain Assessment

- The FLACC is an optional screening that may be offered to parents when pain is reported
- It provides terminology to help parents to describe behaviors they are observing to report to the pediatrician

FLACC Behavioral Pain Assessment Scale

CATEGORIES	SCORING 0	1	2
Face	No particular expression or smile	Occasional grimace or frown; withdrawn, disinterested	Frequent to constant frown, clenched jaw, quivering chin
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs; frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractable	Difficult to console or comfort

How to Use the FLACC

In patients who are awake: observe for 1 to 5 minutes or longer. Observe legs and body uncovered. Reposition patient or observe activity. Assess body for tenseness and tone. Initiate consoling interventions if needed.

In patients who are asleep: observe for 5 minutes or longer. Observe body and legs uncovered. If possible, reposition the patient. Touch the body and assess for tenseness and tone.

Face
- Score 0 if the patient has a relaxed face, makes eye contact, shows interest in surroundings.
- Score 1 if the patient has a worried facial expression, with eyebrows lowered, eyes partially closed, cheeks raised, mouth pursed.
- Score 2 if the patient has deep furrows in the forehead, closed eyes, an open mouth, deep lines around nose and lips.

Legs
- Score 0 if the muscle tone and motion in the limbs are normal.
- Score 1 if patient has increased tone, rigidity, or tension; if there is intermittent flexion or extension of the limbs.
- Score 2 if patient has hypertonicity, the legs are pulled tight, there is exaggerated flexion or extension of the limbs, tremors.

Activity
- Score 0 if the patient moves easily and freely, normal activity or restrictions.
- Score 1 if the patient shifts positions, appears hesitant to move, demonstrates guarding, a tense torso, pressure on a body part.
- Score 2 if the patient is in a fixed position, rocking; demonstrates side-to-side head movement or rubbing of a body part.

Cry
- Score 0 if the patient has no cry or moan, awake or asleep.
- Score 1 if the patient has occasional moans, cries, whimpers, sighs.
- Score 2 if the patient has frequent or continuous moans, cries, grunts.

Consolability
- Score 0 if the patient is calm and does not require consoling.
- Score 1 if the patient responds to comfort by touching or talking in 30 seconds to 1 minute.
- Score 2 if the patient requires constant comforting or is inconsolable.

Whenever feasible, behavioral measurement of pain should be used in conjunction with self-report. When self-report is not possible, interpretation of pain behaviors and decisions regarding treatment of pain require careful consideration of the context in which the pain behaviors are observed.

Interpreting the Behavioral Score

Each category is scored on the 0–2 scale, which results in a total score of 0–10.

0 = Relaxed and comfortable **4–6** = Moderate pain
1–3 = Mild discomfort **7–10** = Severe discomfort or pain or both

From Merkel, S. I., Voepel-Lewis, T., Shayevitz, J. R., & Malviya, S. (1997). The FLACC: A behavioral scale for scoring postoperative pain in young children. Pediatric Nursing, 23(3), 293–297. The FLACC scale was developed by Sandra Merkel, MS, RN, Terri Voepel-Lewis, MS, RN, and Shobha Malviya, MD, at C. S. Mott Children's Hospital, University of Michigan Health System, Ann Arbor, MI. Used with permission.

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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.
  - **Standers-** support passive standing and facilitate weight-bearing.

rifton.com/adaptive-mobility-blog/blog-posts/2013/may

www.especialneeds.com

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

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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.livingmadeeasy.org.uk

Nate8303.blogspot.com

www.1899wheelchair.com

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Assistive Technology in Home Care (cont.)

- Activities of Daily Living (ADL) devices:
  - Bath chairs, Shower chairs, Inflatable bathtubs
  - Specialized potty chairs/ toilet seats
  - Car seats

www.rifton.com

Caleighscorner.com

www.rifton.com

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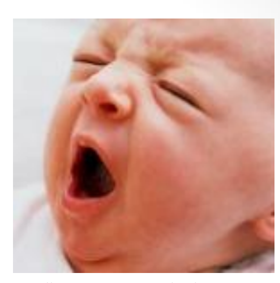
dailymail.co.uk


http://www.awesomekids.com.sg/blog/?page_id=376

Other Issues Frequently Encountered in Home Care

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Developmental Considerations

Medically complex children have particular educational and developmental needs:

- **BIRTH TO 3 SERVICES (ESIT- Early Support for Infants and Toddlers)-** Provide home teacher, family support, home-based therapies, vision/ hearing specific therapies. Administered through the Department of Early Learning. Web site: www.del.wa.gov/esit
- **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

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Primary Care – Role of the Primary Care Provider (PCP)

PCP's play an 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.

En.wikipedia.org

Advance Directives/ POLST forms

- Definitions:

- An Advanced Directive is a legal document used to provide guidance about what types of treatments an individual may want to receive in case of a future, unknown medical emergency. It also allows for the appointment of a health care power of attorney in the event that an individual is not able to communicate for themselves. It is recommended that all adults, healthy or ill, have an Advance Directive. Parents of chronically ill children may benefit from having an Advanced Directive to plan for surrogate caregivers in the event that they are not able to care for their children either temporarily or permanently.

- POLST – Physician Order for Life-Sustaining Treatment is a medical order for the specific medical treatments an individual wants to receive during a medical emergency. POLST Forms are appropriate for individuals with serious illness or advanced frailty near the end-of-life.

  Resource for POLST - https://endoflifewa.org/advance-directive/polst/

Advanced Directive/POLST forms (cont.)

- Who completes an Advance Directives/ POLST forms in Pediatrics:

1) A chronically ill older child or adolescent may be cognitively and emotionally capable of participating in treatment decisions and may decide to complete either an Advance Directive or a POLST form. **Many chronic medical conditions worsen over time. Children with chronic medical conditions experience repeated hospitalizations, treatments, life-threatening emergencies and pain. They observe the death of friends with similar medical conditions. They are often mature beyond their chronological years. They may have thought a lot about the difficulties and joys of their life and they may have definite opinions about what they are willing and unwilling to tolerate. They may desire the opportunity to put in writing directions for their medical providers and caregivers to be sure that their wishes are respected in the event that their condition worsens to the point that they are not able to communicate. (from "Ethical Issues in Homecare" in Guidelines for Pediatric Home Health Care, AAP, 2009)*

2) The family of a chronically or critically ill child may decide it is time to put in writing their wishes for emergency care of their child. They might use the "Pediatric Starter Kit" from the Institute for Healthcare Improvement to help them in their decision making or they might have discussions with the child's primary care provider or palliative care specialist. They would then complete a POLST form.

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HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

Last Name - First Name - Middle Name or Initial

Date of Birth | Last 4 #SSN (optional)

FIRST follow these orders, **THEN** contact physician, nurse practitioner or PA-C. The POLST is a set of medical orders intended to guide medical treatment based on a person's current medical condition and goals. Any section not completed implies full treatment for that section. Completing a POLST form is always voluntary. Everyone shall be treated with dignity and respect.

Medical Conditions/Patient Goals: | Agency Info/Sticker

A (Check One) **CARDIOPULMONARY RESUSCITATION (CPR):** Person has no pulse and is not breathing.
- ☐ Attempt Resuscitation/CPR — When not in cardiopulmonary arrest, go to part B.
- ☐ Do Not Attempt Resuscitation/DNAR (Allow Natural Death) — Choosing DNAR will include appropriate comfort measures.

B (Check One) **MEDICAL INTERVENTIONS:** Person has pulse and/or is breathing.
- ☐ **FULL TREATMENT** - primary goal of prolonging life by all medically effective means. Includes care described below. Use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated. **Transfer** *to hospital if indicated. Includes intensive care.*
- ☐ **SELECTIVE TREATMENT** - goal of treating medical conditions while avoiding burdensome measures. Includes care described below. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not intubate. May use less invasive airway support (e.g. CPAP, BiPAP). **Transfer** *to hospital if indicated. Avoid intensive care if possible.*
- ☐ **COMFORT-FOCUSED TREATMENT** - primary goal of maximizing comfort. Relieve pain and suffering with medication by any route as needed. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Patient prefers no hospital transfer:** *EMS consider contacting medical control to determine if transport is indicated to provide adequate comfort.*

Additional Orders: (e.g. dialysis, etc.) ______

C SIGNATURES: The signatures below verify that these orders are consistent with the patient's medical condition, known preferences and best known information. If signed by a surrogate, the patient must be decisionally incapacitated and the person signing is the legal surrogate.

Discussed with: ☐ Patient ☐ Parent of Minor ☐ Guardian with Health Care Authority ☐ Spouse/Other as authorized by RCW 7.70.065 ☐ Health Care Agent (DPOAHC)

PRINT — Physician/ARNP/PA-C Name | Phone Number

✗ Physician/ARNP/PA-C Signature *(mandatory)* | Date *(mandatory)*

PRINT — Patient or Legal Surrogate Name | Phone Number

✗ Patient or Legal Surrogate Signature *(mandatory)* | Date *(mandatory)*

Person has: ☐ Health Care Directive (living will) ☐ Durable Power of Attorney for Health Care — **Encourage all advance care planning documents to accompany POLST**

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Revised 8/2017 — Photocopies and faxes of signed POLST forms are legal and valid. May make copies for records. For more information on POLST visit www.wsma.org/polst.

WASHINGTON — WSMA Washington State Medical Association — Health

See back of form for non-emergency preferences ►

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Patient and Additional Contact Information (if any)

Patient Name (last, first, middle)	Date of Birth	Phone Number
Name of Guardian, Surrogate or other Contact Person	Relationship	Phone Number

D NON-EMERGENCY MEDICAL TREATMENT PREFERENCES

ANTIBIOTICS:
- ☐ Use antibiotics for prolongation of life.
- ☐ Do not use antibiotics except when needed for symptom management.

MEDICALLY ASSISTED NUTRITION: Always offer food and liquids by mouth if feasible.
- ☐ No medically assisted nutrition by tube.
- ☐ Trial period of medically assisted nutrition by tube. (Goal: ______)
- ☐ Long-term medically assisted nutrition by tube.

ADDITIONAL ORDERS: (e.g. dialysis, blood products, implanted cardiac devices, etc. Attach additional orders if necessary.)

✗ Physician/ARNP/PA-C Signature | Date

✗ Patient or Legal Surrogate Signature | Date

DIRECTIONS FOR HEALTH CARE PROFESSIONALS

Completing POLST · **Using POLST** · **Reviewing POLST**

Review of this POLST Form

Review Date	Reviewer	Location of Review	Review Outcome
			☐ No Change ☐ Form Voided ☐ New form completed
			☐ No Change ☐ Form Voided ☐ New form completed

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Photocopies and faxes of signed POLST forms are legal and valid. May make copies for records. For more information on POLST visit www.wsma.org/polst. OVER ►

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Advanced Care planning- how/ when to bring it up

- Older children/ teens may want to have this discussion but no one has brought it up. Start with questions to allow the teen to discuss their illness, what brings them joy, what they are afraid of, what plans they have for the future, what they are willing and not willing to lose etc…
- For younger children the discussion is with the parents. Discuss the direction of the child's health and ask questions: do the parents see the child as stable, declining, having more hospitalizations and emergencies, requiring more interventions, experiencing more pain or suffering?
- Ask if anyone has discussed Advanced Directives or POLST. Give them resources if interested.
  - https://theconversationproject.org/starter-kits/
- Understand that they may not be ready to discuss this yet and never push; just provide info and let them know you are willing to assist if/ when they are ready.
- Make sure they understand that all decisions about Advance Planning are reversible.

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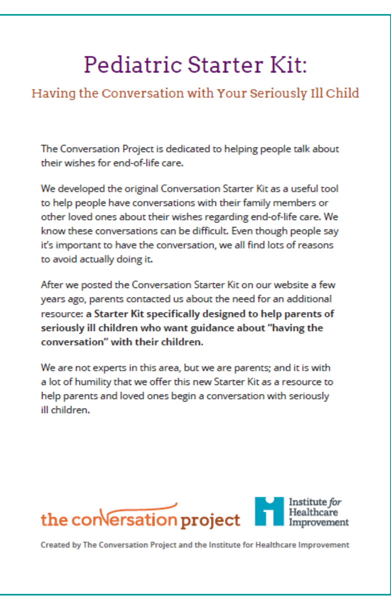
Advance Care Planning (ACP)

Pediatric Starter Kit

https://www.dshs.wa.gov/sites/default/files/ALTSA/stakeholders/documents/duals/toolkit/Pediatric%20Starter%20Kit.pdf

Really excellent resource. Available in English, Spanish and Chinese.
The adult version is available in 11 languages.
Leads families through the stages and process of discussion and advanced planning.
Worth printing out and giving to any interested families.


Pediatric Starter Kit:

Having the Conversation with Your Seriously Ill Child

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We developed the original Conversation Starter Kit as a useful tool to help people have conversations with their family members or other loved ones about their wishes regarding end-of-life care. We know these conversations can be difficult. Even though people say it's important to have the conversation, we all find lots of reasons to avoid actually doing it.

After we posted the Conversation Starter Kit on our website a few years ago, parents contacted us about the need for an additional resource: **a Starter Kit specifically designed to help parents of seriously ill children who want guidance about "having the conversation" with their children.**

We are not experts in this area, but we are parents; and it is with a lot of humility that we offer this new Starter Kit as a resource to help parents and loved ones begin a conversation with seriously ill children.

the conversation project | Institute for Healthcare Improvement

Created by The Conversation Project and the Institute for Healthcare Improvement

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Immunizations

- WA State Immunization Information System - WSII (previously called Child Profile) A registry of vaccinations received by children in WA state. Data electronically transferred from medical clinics throughout the state. All medical offices should be able to access this system and print out a copy of vaccines that a child has received. https://fortress.wa.gov/doh/cpir/iweb/
- Vaccination schedules have become very, very complex. Most clinics have a vaccination nurse who can help the medical provider and family determine which vaccinations are needed.
- The overwhelming majority of children (over 6 months of age) should receive an Influenza vaccine every Fall. This is especially important for children with chronic illness in whom Influenza can be life-threatening.
- Other family members and household contacts should be sure their vaccines are also up to date and they should get an Influenza vaccine every Fall also.

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Pediatric Symptom Checklist - 17

PSC 17- a brief screening questionnaire for use in children 4-16 years of age to improve recognition of mental health problems.
- It is not meant to establish diagnoses but rather to encourage referral to the child's primary care provider or a mental health specialist for further assessment.

Washington State Department of Social & Health Services

Pediatric Symptom Checklist (PSC–17)

Name of Person Completing this Form First Name Last Name	Child's Name First Name Last Name	Date Child's Date of Birth

	Please check the box under the heading that best describes your child or you.			For Office Use Only
	(0) Never	(1) Sometimes	(2) Often	
1. Feels sad, unhappy	☐	☐	☐	
2. Feels hopeless	☐	☐	☐	
3. Is down on self	☐	☐	☐	
4. Worries a lot	☐	☐	☐	Internalizing Total
5. Seems to be having less fun	☐	☐	☐	
6. Fidgety, unable to sit still	☐	☐	☐	
7. Daydreams too much	☐	☐	☐	
8. Distracted easily	☐	☐	☐	
9. Has trouble concentrating	☐	☐	☐	Attention Total
10. Acts as if driven by a motor	☐	☐	☐	
11. Fights with other children	☐	☐	☐	
12. Does not listen to rules	☐	☐	☐	
13. Does not understand other people's feelings	☐	☐	☐	
14. Teases others	☐	☐	☐	
15. Blames others for his/her troubles	☐	☐	☐	
16. Refuses to share	☐	☐	☐	Externalizing Total
17. Takes things that do not belong to him/her	☐	☐	☐	
			Total Score	

A score of 15 or higher may indicate the need for an assessment by a qualified medical or mental health professional.

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PSC-17 (cont.)

- Includes 17 questions – a total score of 15 or higher suggests significant behavior or emotional problems and should lead to the recommendation that the child be seen by their PCP or a mental health specialist.
- The 17 questions are divided into 3 subscales which also have cut-off scores for referral:
  - Internalizing- anxiety and mood disorder, cut-off score of 5
  - Attention- hyperactivity, attention deficit, cut-off score of 7
  - Externalizing – conduct problems, oppositional behavior, cut-off score of 7

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PSC-17 (cont.)

Significantly abnormal PSC-17 result (total score of 15 or higher, or any subscale score exceeding the cut-off) should lead to referral back to the primary care provider for further assessment or referral directly to a mental health provider.

The PCP may have additional screening tools that they use and they will likely conduct a more detailed interview with the child and parent. They may choose to provide counseling in the office or they might refer out to a mental health provider. They might prescribe psychiatric medication themselves or they may refer to psychiatry or to a behavioral pediatrician.

A parent can access Behavioral Health services directly without a referral from the PCP. Some BHO’s provide same-day, walk-in intake evaluations, others require an appointment for the intake. After the intake, if there is a significant mental health issue, the child will be assigned a therapist for ongoing care. A psychiatrist may become involved.

For a county by county guide to the Behavioral Health Organizations in WA state go to the DSHS, Division of Behavioral Health and Recovery website and search for Children’s Behavioral Health, and Mental Health Services for Youth.

https://www.dshs.wa.gov/sites/default/files/BHSIA/dbh/BHO/BHO_Contacts_For_Services.pdf

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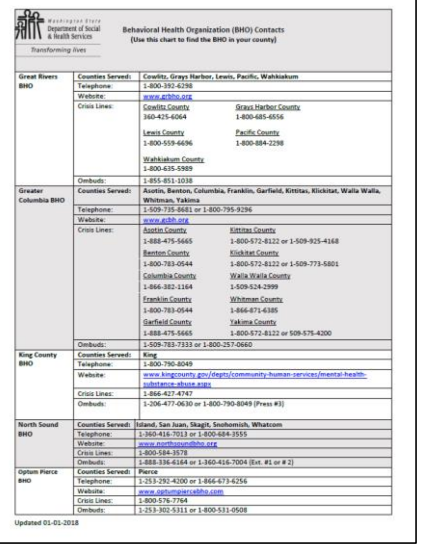
Behavioral Health Organizations (BHOs)

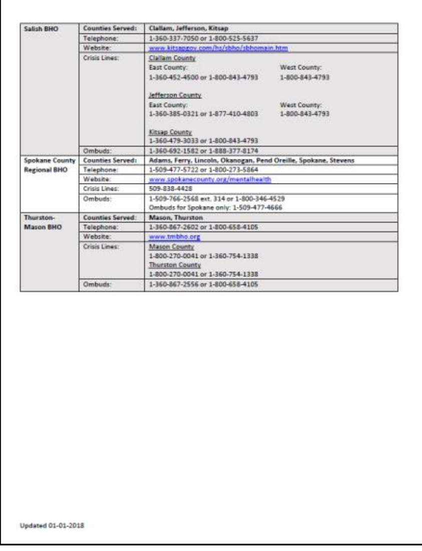


Washington State Department of Social & Health Services
Transforming lives

Behavioral Health Organization (BHO) Contacts
(Use this chart to find the BHO in your county)

BHO		
Great Rivers BHO	Counties Served:	Cowlitz, Grays Harbor, Lewis, Pacific, Wahkiakum
	Telephone:	1-800-392-6298
	Website:	www.grbho.org
	Crisis Lines:	Cowlitz County 360-425-6064; Grays Harbor County 1-800-685-6556; Lewis County 1-800-559-6696; Pacific County 1-800-884-2298; Wahkiakum County 1-800-635-5989
	Ombuds:	1-855-851-1038
Greater Columbia BHO	Counties Served:	Asotin, Benton, Columbia, Franklin, Garfield, Kittitas, Klickitat, Walla Walla, Whitman, Yakima
	Telephone:	1-509-735-8681 or 1-800-795-9296
	Website:	www.gcbh.org
	Crisis Lines:	Asotin County 1-888-475-5665; Kittitas County 1-800-572-8122 or 1-509-925-4168; Benton County 1-800-783-0544; Klickitat County 1-800-572-8122 or 1-509-773-5801; Columbia County 1-866-382-1164; Walla Walla County 1-509-524-2999; Franklin County 1-800-783-0544; Whitman County 1-866-871-6385; Garfield County 1-888-475-5665; Yakima County 1-800-572-8122 or 509-575-4200
	Ombuds:	1-509-783-7333 or 1-800-257-0660
King County BHO	Counties Served:	King
	Telephone:	1-800-790-8049
	Website:	www.kingcounty.gov/depts/community-human-services/mental-health-substance-abuse.aspx
	Crisis Lines:	1-866-427-4747
	Ombuds:	1-206-477-0630 or 1-800-790-8049 (Press #3)
North Sound BHO	Counties Served:	Island, San Juan, Skagit, Snohomish, Whatcom
	Telephone:	1-360-416-7013 or 1-800-684-3555
	Website:	www.northsoundbho.org
	Crisis Lines:	1-800-584-3578
	Ombuds:	1-888-336-6164 or 1-360-416-7004 (Ext. #1 or # 2)
Optum Pierce BHO	Counties Served:	Pierce
	Telephone:	1-253-292-4200 or 1-866-673-6256
	Website:	www.optumpiercebho.com
	Crisis Lines:	1-800-576-7764
	Ombuds:	1-253-302-5311 or 1-800-531-0508

Updated 01-01-2018

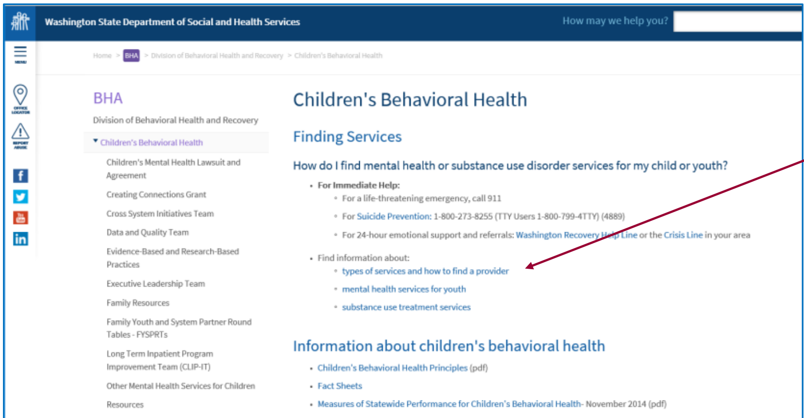


BHO		
Salish BHO	Counties Served:	Clallam, Jefferson, Kitsap
	Telephone:	1-360-337-7050 or 1-800-525-5637
	Website:	www.kitsapgov.com/hs/sbho/sbhomain.htm
	Crisis Lines:	Clallam County East County: 1-360-452-4500 or 1-800-843-4793; West County: 1-800-843-4793; Jefferson County East County: 1-360-385-0321 or 1-877-410-4803; West County: 1-800-843-4793; Kitsap County 1-360-479-3033 or 1-800-843-4793
	Ombuds:	1-360-692-1582 or 1-888-377-8174
Spokane County Regional BHO	Counties Served:	Adams, Ferry, Lincoln, Okanogan, Pend Oreille, Spokane, Stevens
	Telephone:	1-509-477-5722 or 1-800-273-5864
	Website:	www.spokanecounty.org/mentalhealth
	Crisis Lines:	509-838-4428
	Ombuds:	1-509-766-2568 ext. 314 or 1-800-346-4529; Ombuds for Spokane only: 1-509-477-4666
Thurston-Mason BHO	Counties Served:	Mason, Thurston
	Telephone:	1-360-867-2602 or 1-800-658-4105
	Website:	www.tmbho.org
	Crisis Lines:	Mason County 1-800-270-0041 or 1-360-754-1338; Thurston County 1-800-270-0041 or 1-360-754-1338
	Ombuds:	1-360-867-2556 or 1-800-658-4105

Updated 01-01-2018

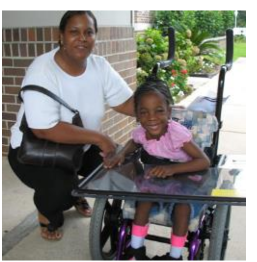
Information About Children's Behavioral Health Services

Link to DSHS Behavioral Health Website: https://www.dshs.wa.gov/bha/division-behavioral-health-and-recovery/childrens-behavioral-health



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


http://www.childrensrehabengineeringteam.com/grants06.htm

http://funtimeswithjoy.blogspot.com/2013_03_01_archive.html

http://kids-with-vents.blogspot.com/2010_08_01_archive.html

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Elias ER, Murphy NA, and the Council on Children with Disabilities. Home Care of Children and Youth with Complex Health Needs and Technology Dependencies. *Pediatrics* 2012:129(5):996-1005.

Feudtner C, Kang TI, Hexem KR, et al. Pedatric Palliative Care Patients: A Prospective Multicenter Cohort Study. *Pediatrics* 2011:127(6):1094-1101.

Kang TI, Munson D, Hwang J, Feudtner C. Integration of Palliative Care Into the Care of Children with Serious Illness. *Pediatrics in Review* 2014:35(8):318-325.

Peterson-Carmichael SL, Cheifetz IM. The Chronically Critically Ill Patient: Pediatric Considerations. *Respiratory Care.* 2012:57(6): 993-1003.

Walter JK, Ross DeCamp L, Warrier KS, Murphy TP, Keefer PM. Care of the Complex Chronically Ill Child by Generalist Pediatricians: Lessons Learned From Pediatric Palliative Care. *Hospital Pediatrics.* 2013:3(2):129-138.

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Resources

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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-tracheostomy-ventilator-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 http://ocde.us/Health/Documents/CSUF%20Skills%20Lab/Skills%20Lab%20Trach%20Care.pdf

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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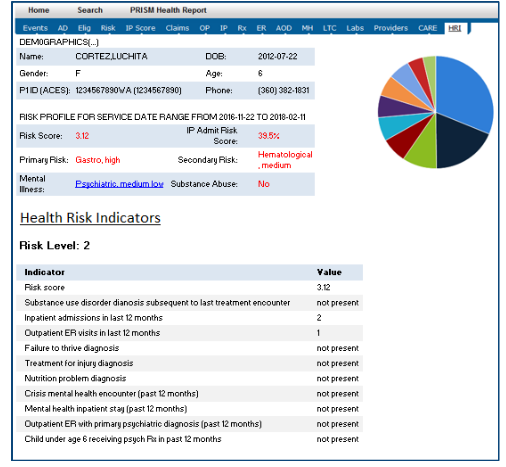
PRISM Health Risk Indicators (HRI)



Home | Search | PRISM Health Report

Events | AD | Elig | Risk | IP Score | Claims | OP | IP | Rx | ER | AOD | MH | LTC | Labs | Providers | CARE | HRI

DEMOGRAPHICS(...)

Name:	CORTEZ,LUCHITA	DOB:	2012-07-22
Gender:	F	Age:	6
P1 ID (ACES):	1234567890WA (1234567890)	Phone:	(360) 382-1831

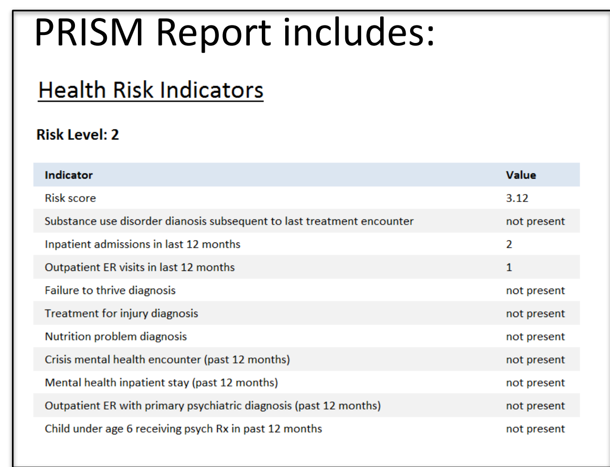
RISK PROFILE FOR SERVICE DATE RANGE FROM 2016-11-22 TO 2018-02-11

Risk Score:	3.12	IP Admit Risk Score:	39.5%
Primary Risk:	Gastro, high	Secondary Risk:	Hematological , medium
Mental Illness:	Psychiatric, medium low	Substance Abuse:	No

Health Risk Indicators

Risk Level: 2

Indicator	Value
Risk score	3.12
Substance use disorder dianosis subsequent to last treatment encounter	not present
Inpatient admissions in last 12 months	2
Outpatient ER visits in last 12 months	1
Failure to thrive diagnosis	not present
Treatment for injury diagnosis	not present
Nutrition problem diagnosis	not present
Crisis mental health encounter (past 12 months)	not present
Mental health inpatient stay (past 12 months)	not present
Outpatient ER with primary psychiatric diagnosis (past 12 months)	not present
Child under age 6 receiving psych Rx in past 12 months	not present



PRISM Report includes:

Health Risk Indicators

Risk Level: 2

Indicator	Value
Risk score	3.12
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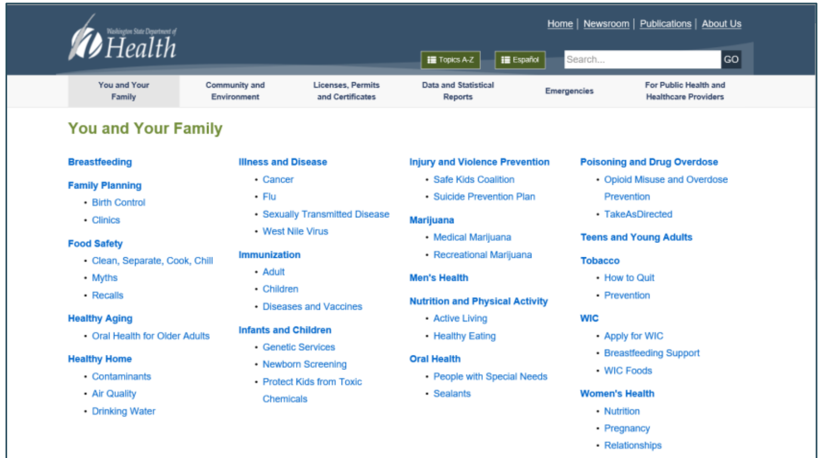
Washington State Department of Health



https://www.doh.wa.gov/YouandYourFamily

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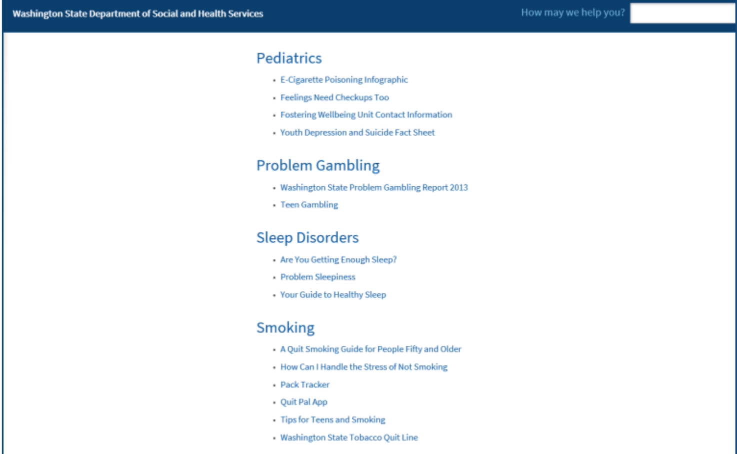
Care Coordinators Toolkit



https://www.dshs.wa.gov/altsa/stakeholders/chronic-disease-and-education-materials

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