

Life Care Planning for Children Requiring Home Mechanical Ventilation

Disclosures

- I have no financial interests or relationships to disclose.
- The upcoming scenario has been drastically altered and in no way implies real patient information or a breach in confidentiality.



My Role

- Pediatric Nurse 36 years
- Nurse Practitioner 16 years
- Testifying Expert 10 years
- CNLCP – “priceless”

- Mechanically ventilated children – invasive/non-invasive
- Trach dependent
- Feeding tubes/Brain shunts/Vascular access/Ostomies/Catheters ...

I SEND THEM HOME!!!!

Objectives

- Identify two important goals for a child receiving home mechanical ventilation via tracheostomy tube.
- List one education requirement that must be met by the caregiver prior to a child going home with a ventilator.
- List three main types of durable medical equipment (DME) technology dependent children and young adults require to improve or maintain their ability to function in everyday life.
- Name one organization that supports parents of children requiring mechanical ventilation.
- Review how technology dependence affects specific aspects of the lives of children and their families.



INTRODUCTION

Growing population of children dependent on mechanical ventilation (MV)

Advancing technology supports ventilation in the home.

Many children on MV can still lead productive lives



WHO???

WITH PERMISSION- CINCINNATI CHILDRENS HOSPITAL

WHAT?



Mechanical ventilation or positive pressure ventilation is the treatment modality for chronic respiratory insufficiency or failure

WHEN??

DAYTIME

NIGHT TIME

ALL THE TIME

WHERE?



WHY???

- Conditions that affect the lung parenchyma and airway such as Bronchopulmonary dysplasia (prematurity), tracheobronchomalacia, interstitial lung disease
- Neuromuscular disorders of the brain and spine such as hypoxic ischemic encephalopathy, cerebral palsy, traumatic brain or spinal cord injury.
- Chest wall disorders such as spinal muscular atrophy, achondroplasia, severe scoliosis

HOW??

NON-INVASIVE

MASK, NASAL PILLOWS

INVASIVE

TRACHEOSTOMY TUBE

EXAMPLE...Near Drowning Scenario

Haley

- 4 y.o. female otherwise healthy
- Left at home with babysitter while single mom at work
- Found floating in family pool for unknown amount of time
- Resuscitated at scene by EMS
- ER: CPR x 7 min, 4 doses Epi, Asystole, PEA, Vfib

Pediatric ICU stay

- 2 months- intubated and subsequent tracheostomy tube placement
- Mechanical ventilation
- Nasogastric/Gastrostomy tube
- Arterial line, CVC, PICC
- 1 Code Event

Nursing Diagnosis- Acute Care

- Ineffective cerebral tissue perfusion
- Impaired gas exchange/hypoxemia
- Risk for infection
- Bronchospasm
- Risk for cardiac arrhythmias
- Fluid volume deficit/overload

Beyond the PICU

- No longer needing ICU care
- Begin the rehabilitation process
- Begin teaching the family how to manage care
- Make plans for discharge home

Medical Diagnosis- Chronic Care

- HIE (hypoxic-ischemic encephalopathy) -2021 ICD-10-CM CODE P91.63
- Tracheostomy dependence--2021 ICD-10-CM Code Z93.0
- Ventilator dependence-2021 ICD-10-CM CODE Z99.11
- Dysautonomia-2021 ICD-10-CM CODE G90.1
- Choreiform movements-2021 ICD-10-CM CODE F82
- Seizures-2021 ICD-10-CM CODE G40.109
- Cortical visual impairment-2021 ICD-10-CM CODE H54.7
- Feeding by Gastrostomy-2021 ICD-10-CM CODE Z93.1
- Neurogenic bowel and bladder-2021 ICD-10-CM CODE K59.2, 2021 ICD-10-CM CODE N31.2
- Educational Circumstance-2021 ICD-10-CM CODE Z76.89
- Inadequate Social Support-2021 ICD-10-CM CODE Z59.9

Nursing Diagnosis- Chronic Care

- Risk for decannulation r/t tracheostomy
- Impaired communication r/t tracheostomy
- Risk for impaired gas exchange r/t need for mechanical ventilation
- Risk for infection r/t ineffective airway clearance, neurogenic bladder (intermittent straight cath)
- Risk for aspiration r/t ineffective swallow, poor feeding intolerance, seizure disorder
- Risk for alteration in skin integrity r/t technology hardware ie: trach tube, GT, ventilation circuit, loss of mobility
- Risk for caregiver role strain r/t chronic medical needs and safety requirements

Transfer Goals on Transitional Care Unit



Medical
Stability

Caregiver
Education

Transition
to
Home

What does “**Medical Stability**” look like?



What does “Caregiver Education” look like?



What does “Transition to Home” look like?



Main Goal

Avoid hospital readmissions!!



Re-admissions

- Frequent in children on mechanical ventilation, why?
- Lack of home nursing/need for respite
- Risk of respiratory distress is high
- No where to escalate care beyond increasing treatments
- Very labile children

Re-admissions

- Lose nursing help and then you get stuck for discharging home
- Rarely a thing as “in and out” admission
- Most always requires an ambulance for transportation
- Risk for nosocomial infection
- Cost is huge, especially if admissions require ICU care.

Routine day

Treatments and Airway clearance

Feeding schedule

Bathing, trach care, GT care

Activity- TV, computer, school, therapies

Feeding schedule

Bathing, trach care, GT care

Treatments and Airway clearance

Treatments and Airway Clearance

- Inhaled medications/saline- inhalers and/or nebulization(inline or by trach collar)
- Chest physiotherapy- Vest, Volara, Manual
- Cough assist
- Suction- open and inline
- Oxygen- through the vent, O ring, trach collar
- Humidification- water chamber, trach collar, HME, room humidification

Feeding

Some kids can eat by mouth- may need adaptive cutlery, bottle, nipples, table

NG/ND/NJ- replacement tubes, ER visits, feeding pump and supplies

GT/GJT- replacement tubes, ER visits, feeding pump and supplies, skin barriers

TPN- elevated level of need to include RN's. (most often not at home)

Feeding

- Nutrition evaluation with dietician to evaluate growth. Every month to year depending on growth and age of child.
- May require periodic swallow evaluation based on oral intake and age.
 - Video Swallow study- (VSS) with speech therapist
 - Functional Endoscopic Evaluation of Swallow (FEES) with ENT MD
 - Upper GI
 - Gastrostomy tube re-placement in radiology s/p dislodgment or upsize based on growth

Bathing

- Depends on age and size of child. Main goal is to avoid water in trach at all costs.
- Bed mattress cover
- Infant tub
- Shower chair, shower accommodations for wheelchair, hand held sprayers, shower bib
- May need special soaps and lotions, skin barriers

Medications

- Routine & PRN
- Oral, tube, inhaled, rectal, rarely injectable but may be.
- Medication syringes, supplies for inhalation

Tracheostomy Tubes

Adult VS Pediatric Main Differences

Pediatrics

- Due to the small size - pediatric tracheostomy tubes are single lumen
- There are also no fenestrated tracheostomy tubes available for the pediatric population.

Adult

- Adult tracheostomy tubes have an inner cannula or “double lumen” that can be removed and cleaned while the base of the trach remains in the neck.
- A fenestrated trach tube is simply a term that refers to the hole or opening in the shaft of the tube. This allows for phonation and cough.



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Tracheostomy Tubes

There are many types and brands of tracheostomy tubes.
(e.g. Bivona, Shiley, Tracoe)

The tubes come in many sizes and lengths determined by
the physician.

Size: 2.5-5.5 mm internal diameter
Length: 30-36mm for neonates and
39-56mm for pediatrics

The trach tube or cannula can be uncuffed or cuffed.

(Cuffed trachs are used by children who are on
mechanical ventilation)



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Trach Safety

- Eyes on child at all times
- Same size trach and half size smaller at bedside or in reach at all times
- Emergency bag should always be with the child. Should have extra trachs. Patients usually have 3 same size trachs + the trach in their neck.
- Trachs can be cleaned (usually 5 times) before disposal- check manufacturer instructions.
- Custom trachs are much more expensive. Typically, can use non-custom as your back up trach. (Physician directed)

Ventilators

- Hospital Ventilators
- Home Ventilation
- Portable Ventilation
- Mode of Ventilation
- Brands (Pulmonetic, Phillips, Ventec)
- Replacement- typically rent/rent to own/replacement every 5 years or longer.
- Ventilation circuits
- Ventilator stand for bedside

Safety and Mobility

- Never should a child be left alone. Eyes on child at all times. Avoid smoking esp inside the home.
- EMS- Meet and Greet
- Should not be using a CPAP/BIPAP machine on a pediatric patient due to lack of alarms. Should be a full -fledged ventilator.
- Small children can use a stroller for transportation. Should be able to accommodate all of their equipment. (Vent, suction machine, pulse oximeter)
- Wheelchair/Kidcart- typically new chair every 5 years. Electronic is used when child is able to control himself/weight of child is too much for parent.
- Car seat- rear facing, 3-5 point harness. Need to be able to also secure equipment to the floor.
- Vehicle modifications
- Lift system- home
- Orthotics and Braces, walkers, standers, wagon
- Handicap Placard

Durable Medical Equipment

- 2 mechanical ventilators w/ batteries
- Ventilator stand for bedside
- Airway clearance machine/cough assist
- Monitoring equipment (Pulse oximeter)
- Nebulizer
- Tracheostomy Tubes
- Suction Machine- home and portable
- Oxygen- home & portable
- Humidification/Heated humidification
- Emergency bag
- Feeding pump-home and portable
- Wheelchair

Supplies

- Disposable saline vials
- Suction catheter kits
- Ambu bag
- Cotton swabs
- Trach ties
- Masks/Gloves
- Nebulizer supplies for medication delivery
- Oxygen tubing
- Pulse oximeter probes
- HME/PMV (for kids off ventilator)
- Skin care dressings
- Incontinence supplies, diapers, wipes
- Feeding tube replacements, feeding supplies
- Enteral nutrition/formula
- Sterile water
- May need backpack to carry ventilator and/or feeding pump.

Pediatric Rehabilitation

- There are no specific tools that therapists use for children on mechanical ventilation.
- There are multiple medical, emotional, educational and rehab requirements for all children on mechanical ventilation so it requires a team of people to determine plan.
- Upright positioning/standing is important for bone density, head molding and should be encouraged.
- Orthotics are indicated to manage contractures, alignment of trunk and extremities, and joint flexibility. When using bracing of spine, must allow for chest wall expansion.

Communication

- Computer /laptop/Ipad
- TV/DVD
- Communication board
- Passy Muir Valve (speaking valve) if indicated
- Glasses for vision impairment if prescribed
- Sign language
- Constant monitoring

Therapy

- PT, OT, Speech- 2-3 times/week each therapy.
- Home therapists must be familiar with alarms, emergency supplies and knowledgeable about children with trach tube and home ventilation.
- Home therapy is preferred due to difficulty in making ventilated children portable.
- Children should have some sort of daily activity especially if not in school.

Home nursing- Trained Caregivers

- In a perfect world- RN but 99% of the time LPN/LVN.
- MUST be trained in Trach/Vent, classes by home care company. There are no certifications as of yet. Must be able to display competency
- Must know and be trained in CPR of the child with a tracheostomy tube.
- Home care companies that specialize in Pediatric cases. Many children's hospitals have their own HHC.
- Will need someone to take child to school unless other arrangements are made with the school district in IEP.
- 24 hour/day, 7 days a week. Parent can own 8 hours of the day. Most insurance co. approve 16 hours/day x 7 days.
- 7 nights of coverage is standard of care.
- Qualifications, licensed, educated, No cert, cpr with trach, competent

Community

- School/IEP
- Emergency Medical services
- Support groups
- There are overnight and day camps available in some areas for children on ventilators.

Follow up

- Follow up medical visits- every 3-6 months per specialty service or as indicated
- Therapies 2-3 times/week per therapy (PT/OT/ST)
- Child will still need a pediatrician and all the appropriate normal development follow up for immunizations, screening etc.

FU Providers- Collaboration is key

- Pediatrician, ENT, Pulmonary, Neurology, GI, GU, Rehab, Genetics, Neurosurgery and/or Surgery, Orthopedics
- Some kids have a complex care team/medical home
- Airway evaluations every 3-12 months
- Labs- Usually just yearly and provider /diagnosis specific. General labs, blood gas.
- Sleep study, CXR, Chest CT, MRI, Spine Xray, Botox
- Telemedicine
- Understand length of ventilator use and if weaning is part of the plan

Coding and Costing Considerations- Tracheostomy Tube

- **When looking for a trach tube cost. You will need to know if the tube is :**
- Standard or custom
- Neonatal or Pediatric or Adult
- Cuffed or uncuffed
- Size of tube (inner diameter in mm) and length of tube
- Low profile or extend connect
- Water cuff or air cuff
- Manufacturer
- Quantity- 3-4 (same size) 2 (one size smaller)
- Change every 2 weeks (scheduled) but will depend on MD order. Can be cleaned and reused x 5 or per manufacturer recommendation
- Therefore, its best to get the **actual cost**. ENT department are typically the people that order this product because is children, it is **that** specific.

Tracheostomy Tube Supplies

- HME (Heat moisture exchanger) 100/mo.
- PMV (Passy Muir Valves) if using 2/mo
- Trach ties/holder- 30/mo
- Suction catheters- size in French and quantity 150/mo if they have open suction. May have inline suction- 30/mo.
- Gloves if needed and not a suction cath kit- 1 box/mo.
- Cotton tip applicators 1 box/mo
- 2x2 and 4x4 gauze 2 boxes each/mo
- Surgilube- 2 pkg /mo
- Sodium chloride bullets- 90/mo
- Mepilex lite 6x6 barrier- 10/mo

Coding and Costing Considerations- Ventilators

- Manufacturer of home vent
- Determine if there is a need for one or two ventilators
- Rent/Own/Rent to Own
- Will need to talk to the DME company re: replacement timing but ventilators are typically ordered by provider as “Lifetime”
- Back up batteries – 1 per ventilator
- Associated supplies to include heater, water reservoir, circuit, connectors. Will be different on different vents. Some are single limb and some are double limb.
- Need some attachment or way to secure on their wheelchair, stand.

Ventilator Supplies

- All dependent on type of ventilator ordered (Typical)*
- Heater -1/mo*
- Auto fill chamber -2/mo*
- Sterile water for humidifier- 36/mo*
- Heated wire circuit/tubing -2/mo*
- Omniflex connect- 4/mo*
- Trach swivel- 4/mo*
- Transport circuit- 1/mo*
- HME for transport-2/mo*
- Oxygen adapter for vent- 1/mo*

Complications/Emergencies

- Respite
- EMS
- Readmissions (pneumonia, aspiration, bleeding from trach, mucous plug, accidental decannulation, bronchospasm)
- Maintaining a good group of home nurses
- Illness and testing
- Sick plan

School

Office for Civil Rights (OCR) enforces Section 504 of Rehabilitation Act of 1973

- Statute which prohibits discrimination against individuals with disabilities.

Office of Special Education and Rehabilitative Services (OSERS) administer the Individuals with Disabilities Education act IDEA

- Statute which funds special education programs. Each state is responsible for administering IDEA within the state and distributing the funds for the special education programs
- IEP- determines the plan of care and education
- Nursing- skilled, trained nurse must accompany child at all times
- Bus- may ride the bus with skilled nurse.

Resources for Parents

- Facebook groups- Kids with Vents and Moms of Trach babies
- Global TrachCollaborative- Research medical group that includes families.
- Disease specific support groups
- Hospital resource centers
- Respite centers

Other Considerations- Future

- Developmental age and size- changes in medical condition will require ongoing re-evaluation. Collaborate to know possible future complications/surgeries
- Ongoing therapies may be at the school
- School IEP, academic support through high school
- Loss of one parent work to be a trained caregiver
- Siblings
- Respite
- Family vacations with additional help

Other Considerations

- Storage for supplies and equipment
- Van/handicap home
- Bed
- Wheelchair, mobility ongoing support
- Psyche- social isolation, disrupted sleep, chronic fatigue, low self esteem
neuropsych testing
- Computer, phones, home automation
- Life expectancy number – Genetics or Pulmonary MD
- Case manager

It Takes a Village

- Please contact Marsha Blount APRN if you need help, would like to discuss coding and costing!! I am always willing to help you out!

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