

*As the population of ventilator-dependent children with tracheostomies grows, there are increasing demands to shift the care of technology-dependent children from hospital to home. Home care nurses are an integral part in the continuum of care for these children and their families after hospital discharge. Home care nurses help to facilitate a safe transition from the hospital and allow families and children to thrive in their home and community. The purpose of this article is to describe best practices in caring for children with tracheostomies and invasive home mechanical ventilation. Hypothetical case studies are presented.*

# The Ventilator-Dependent Child

## *What Every Home Care Nurse Needs to Know*

**I**t is estimated that more than 8,000 children receive home mechanical ventilation (HMV) in the United States (Boroughs & Dougherty, 2016). Despite increasing numbers of ventilator-dependent children managed at home (Figure 1), the percentage of preventable deaths has remained largely unchanged at 27.5% (Boroughs & Dougherty, 2012), and 49% of deaths are unexpected (Edwards et al., 2010). Boroughs and Dougherty (2012) identified three primary causes of preventable death in homebound ventilator-dependent children. These include: (1) inadequate training (lack of familiarity with tracheostomy changes, ventilator alarm, and circuit troubleshooting), (2) improper response (failure to recognize an obstructed or dislodged tracheostomy tube, medical device failure), and (3) lack of vigilance (asleep, alarm fatigue). The purpose of this article is to provide

pediatric home care nurses (HCNs) with best practices in caring for children with tracheostomies and invasive HMV.

### The In-Home Experience

#### **Start of Shift: Patient Report, Assessment, and Safety Checks**

Handing off the care of a home care patient from one caregiver to another is no less important than for a hospital patient, and should be an integral part of the daily routine in pediatric home care (Anderson, 2018). Up to 80% of serious healthcare errors may be attributed to miscommunication during the transfer of care (Joint Commission, 2012). Home care nurses assigned to care for children on HMV should arrive 10 minutes prior to the start of their shift to receive report. Generally, this provides ample time for a verbal hand-off from the previous caregiver. A standardized hand-off tool

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can decrease information overload, improve the quality of information exchanged, and improve patient outcomes (Galatzan & Carrington, 2018). The I-PASS is an example of a tool that has been found to improve the quality of hand-offs (Starmer et al., 2017). This acronym stands for I: Illness severity, P: Patient summary, A: Action list, S: Situation awareness and contingency planning, S: Synthesis by receiver. The HCN should also encourage the family to be present for, and participate in, nurse-to-nurse hand-offs. In addition to the verbal hand-off, use a bedside communication notebook to summarize the report for oncoming caregivers.

The next step in assuring patient safety is an initial patient assessment. This establishes a clinical baseline at the beginning of the shift, and promotes early recognition of signs and symptoms reflective of a deteriorating status. Use the Pediatric Assessment Triangle for assessment. Note the child's appearance, work of breathing, and circulation. Appearance is assessed by skin color, muscle tone, interactivity, consolability, look/gaze, and speech/cry. Work of breathing is evaluated by listening for abnormal breath sounds, noting body positioning, presence of retractions, and nasal flaring. Observe circulation by looking for pallor, mottling, cyanosis, and bleeding (Auerbach et al., 2016).

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After initial patient assessment, safety checks should be performed on emergency equipment and medical devices as described in Tables 1, 2, and 3. During an emergency, discovering that a vital piece of equipment is missing or inoperative could have fatal consequences. Never assume that the emergency bag is well supplied or that the equipment is properly functioning without first checking it. A long period of patient stability may foster a false sense of security that consequently results in overlooking some of the mundane but essential daily checks that are required for basic patient safety. Weeks or months may go by without a crisis, but a child can suddenly present with a life-threatening situation. A regimen that starts every shift with patient assessment and safety checks will improve outcomes for high-risk children.

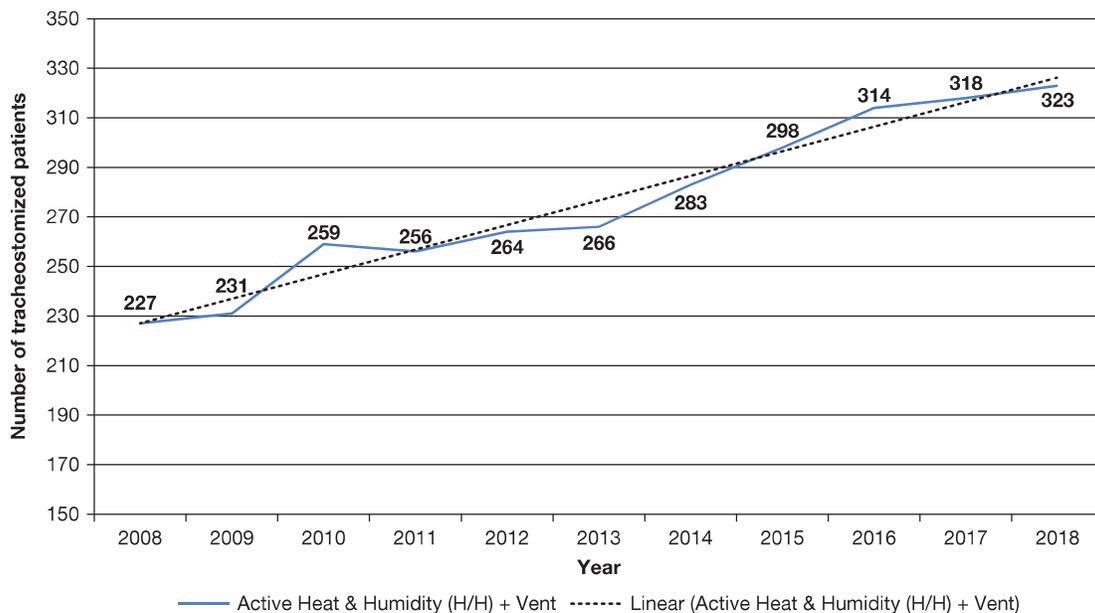
### Emergency Response

**Obstructed tracheostomy tube.** An obstructed tracheostomy tube may present with respiratory distress, color change, a drop in oxygen saturations, activated ventilator alarms, and increased work of breathing. When an obstructed tracheostomy tube is suspected:

1. Visualize the tracheostomy tube and stoma to ensure the tube has not dislodged. If dislodged and the patient is in distress, immediately reinsert the dislodged tube (see accidental decannulation below). Do not waste time searching for a new sterile tracheostomy tube. If the tracheostomy tube is not dislodged, suction the tracheostomy tube, then reconnect to the ventilator to assess for proper ventilation.
2. If the patient is still in distress, initiate the *Bag—Irrigate—Bag—Suction* (BIBS) protocol:
  - Bag: remove the patient from the ventilator and attempt to manually ventilate using the resuscitation bag, and if available, supplemental oxygen.
  - Irrigate: apply a few drops of normal saline to the airway.
  - Bag: manually ventilate the patient with 3 to 4 breaths to loosen secretions.

- Suction: use safe suction depth technique to clear the tracheostomy tube. After suctioning, attempt to manually ventilate again with the resuscitation bag to reassess the airway status and look for chest rise.
3. If the patient continues to be in distress, perform an emergency tracheostomy tube change. After inserting the new tracheostomy tube, manually ventilate using the resuscitation bag.
  4. Resume mechanical ventilation if the airway status improves and the patient is stable.
  5. Call 911 if still unable to manually ventilate after the tracheostomy tube change. While waiting for emergency help, attempt the BIBS protocol again, but this time advance the suction catheter to twice the prescribed safe suction depth, or until meeting resistance and suction.
  6. Attempt to ventilate after each pass of the suction catheter and look for chest rise.

**Accidental decannulation.** An accidental decannulation may present with respiratory distress, color change, a drop in oxygen saturations, activated ventilator alarms, and increased work of



**Figure 1.** Prevalence of tracheostomized patients at PHS.

Source: Pediatric Home Service, Roseville, Minnesota.

**Table 1. Bedside Emergency Equipment Checks**

If a patient were to have an airway emergency at start of shift, what supplies do you need to have ready to go?

Primary Emergency Checks	
Equipment	Checks
<b>Emergency supplies and emergency bag (e-bag)</b>	Emergency supplies and equipment, tracheostomy tubes are within reach at the bedside and in the emergency bag. A flashlight is readily accessible.
<b>Stationary and portable suction</b>	Correct suction pressure is set, proper catheters available, suction machine is plugged in and charging, back up manual suction device. A DeLee suction trap is available if suction machine is nonfunctioning.
<b>Resuscitation bag</b>	Located in e-bag and bedside within reach, intact and create pressure when occluded, correct PEEP valve setting, auxiliary ports closed, pop-off valve is working, oxygen tubing connected to bedside tank, proper size mask usable and accessible.
<b>Emergency oxygen supply</b>	Properly connected to ventilator and resuscitation bag, O <sub>2</sub> tank is full, wrench, connectors, and adapters accessible.
<b>Ventilator</b>	Primary and secondary settings reviewed and correct on main and backup ventilator, test lung available, equipment is plugged in and charging, backup set of tubing assembled and accessible.
<b>Pulse oximeter</b>	Proper probe placement, good waveform, review of prescribed alarm settings, disconnect oximeter to ensure that alarms are functioning and can be heard from anywhere in the home, available replacement probes, equipment is plugged in and charging.
<b>Medications</b>	Emergency meds in the correct doses are easily accessible at bedside and in emergency bag, expiration dates current.
<b>Infusion therapy pump</b>	Adequate supplies, review prescribed medications and doses, power supply cable, and battery charge status of pump.
<b>Communication</b>	Phone(s) are working and charged, emergency phone numbers and patient's home address in view.
Secondary Emergency Checks	
Equipment	Checks
<b>Oxygen supply</b>	Ensure adequate oxygen supply in the home based on patient need and plan of care.
<b>Food pump</b>	Adequate supplies of formula and feeding bags; check power supply cable and battery charge status of pump.
<b>Monitoring devices</b>	Blood pressure monitor, end-tidal CO <sub>2</sub> monitor, glucometer, etc., have a power supply, device is properly working.
<b>Nebulizer</b>	Compressor and neb cup properly working, new cup and medications available, oxygen tank available to use during a power outage to run nebs.

Note. PEEP = positive end-expiratory pressure. Pediatric Home Service, Roseville, Minnesota.

breathing. Hearing audible noises from a child who previously couldn't vocalize is also a sign of accidental decannulation. When accidental decannulation occurs:

1. Loosen or remove tracheostomy ties.
2. Use the tracheostomy tube obturator that is kept taped to the top of the ventilator, or at the bedside, and insert it into the tracheostomy tube. If the child is having respiratory distress, reuse the dislodged tracheostomy tube rather than searching for a new one.
3. Slightly extend the child's neck to visualize the tracheostomy stoma.
4. Carefully insert the tracheostomy tube, but do not force.
5. If unable to insert the tracheostomy tube, remove the next size smaller tracheostomy tube from the emergency bag and insert.
6. If unable to insert the downsized tracheostomy tube, occlude the tracheostomy stoma with gauze or gloved hand and use face mask and resuscitation bag to ventilate the child, unless the child has a tracheal diversion. In that case, follow the child's protocol.
7. Start cardiopulmonary resuscitation, if needed, and call 911.

See Supplemental Digital Content 1 (available at <http://links.lww.com/HHN/A122>) for an example of a safety card on this topic.

**Emergency medical services (EMS).** Clear communication between the HCN and the EMS team is key to optimizing patient outcomes during an emergency situation. Following an urgent 911 call, the HCN should continue emergency interventions outlined in the physician-prescribed home care orders. When EMS arrives, the HCN should work with the EMS team, which may have limited experience with medical emergencies in a complex ventilator-dependent child. Initial collaboration includes providing a thorough report that communicates events that precipitated the urgent situation, medications administered, emergency actions already taken, and current patient status. Assist in stabilizing the patient on the home ventilator if necessary for medical transport or facilitating intravenous access if the patient has a central venous catheter. A one-page document that delineates diagnoses, medications, and therapies should be kept in the home to provide to EMS workers (Supplemental Digital Content 2, available at <http://links.lww.com/HHN/A124>).

**Medical equipment alarms.** Medical devices have alarms to alert caregivers and enhance patient safety. An overabundance of “beeping” contributes to desensitization, alarm fatigue, and

**Table 2. Emergency Bag Contents**

Item	Quantity
Resuscitation bag and mask	1
Heat moisture exchangers (HME) with oxygen adaptor	4 HME, 1 oxygen adaptor
Unopened bottle of sterile water	1 small bottle
Proper size suction catheters	10
Nonsterile gloves	5 pair (M, L, and XL)
Oximeter probe	1 unopened
Stethoscope	1
Tape and dressing	Specific to patient
Feeding tube supplies	To meet safe care plan
Emergency medications and protocols	As written in care plan
Spare tracheostomy tubes and supplies	In easily identifiable container

Note. Pediatric Home Service, Roseville, Minnesota.

**Table 3. Tracheostomy Tubes and Supplies in an Easily Identifiable Container**

Item	Quantity
Proper size tracheostomy tube	1
One size smaller tracheostomy tube	1
Luer tip syringe to deflate cuff	1 (if using a cuffed tracheostomy tube)
Proper size suction catheter for main tracheostomy tube	1
Size smaller suction catheter for smaller tracheostomy tube	1
Trach securing device	2
Saline vials	6
Lubricant packets	4
DeLee manual suction catheter (proper size)	1
Scissors	1
Forceps	1
Wire cutter if using a beaded chain securing device	1

Note. Pediatric Home Service, Roseville, Minnesota.

a subsequent lack of vigilance in patient care. Proper training in safe alarm management and response is essential. One approach to minimize alarm fatigue is to discuss customization of the alarm parameters with the care team. This strategy may reduce false alarms without jeopardizing patient safety. When alerted by a pulse oximeter or ventilator alarm, the primary focus should be on the patient and every alarm should be responded to.

### Ventilator Alarms

1. Is the problem obvious? Can it be fixed in less than 3 seconds (e.g., tubing has become disconnected)?
2. If the problem cannot be fixed in less than 3 seconds, take the patient off the ventilator and ensure they are well supported with a resuscitation bag and oxygen as needed.
  - Further interventions may include suction, BIBS protocol, or changing the tracheostomy tube to establish a clear airway.
  - If the airway is clear, support the patient with a resuscitation bag or the backup ventilator. Request help from a family caregiver, if available.

3. The focus should be on the patient, not the medical device, and the associated alarm(s).
  - Always attend to the patient's needs first by "Listen, Look, See...Respond to Me!" (Supplemental Digital Content 3, available at <http://links.lww.com/HHN/A123>).
  - If the patient is stable and supported off the alarming or problematic ventilator, consider silencing the alarm if it is distracting during troubleshooting.
4. Place the ventilator on the test lung to troubleshoot. If alarms continue while on the test lung, the problem is the ventilator or tubing.
  - Check all connections, look for water in the tubing, including sensors, pressure lines, whisper swivel, or exhalation valve. Holes in vent tubing may be audible.
  - If the problem persists without resolution, place the patient on the backup ventilator and call the equipment provider to help with troubleshooting.

#### Pulse Oximeter Alarms

1. First look at the patient! Does the patient appear cyanotic or in distress consistent with the alarms?
2. Look at the tracheostomy stoma to verify the patient has not accidentally decannulated.
3. Ensure the ventilator is connected to the patient, oxygen supply is adequate, and oxygen tubing is connected with proper flow.
4. Assess for airway obstruction. This includes looking for chest rise with spontaneous or ventilator breaths or chest rise when ventilating with a resuscitation bag. High-peak pressure alarms on ventilator-dependent patients may also indicate lower airway obstruction.
5. Verify the oximeter probe is in the proper position and working. The probe may need to be repositioned or changed.
6. Follow the patient care plan for administration of oxygen.

#### Case Studies With Clinical Pearls

The following hypothetical case studies are based on the authors' experiences with adverse events encountered in pediatric home care.

##### Case Study 1: Occluded Tracheostomy Tube

John is a tracheostomized and ventilator-dependent 14-year-old with Duchenne muscular



**Figure 2.** Catheter pushed through plug. The suction catheter passes through the mucous plug, but the plug is not removed during the return suction.

Pediatric Home Service. (2019). Roseville, Minnesota.



**Figure 3.** Mucous plug returns.

Mucus plug continues to occlude the inner lumen of the tracheostomy tube after the suction catheter has been withdrawn.

Pediatric Home Service. (2019). Roseville, Minnesota.

dystrophy. He begins developing respiratory distress characteristic of his need for airway suctioning. After two passes of the suction catheter to a safe suction depth of 1 cm beyond the distal tip of the tracheostomy tube, scant amounts of mucus are aspirated, but his distress continues. The patient remains in distress despite minimal lavage, ventilating with a resuscitation bag and oxygen, and repeat suctioning. Performing an emergency tracheostomy tube change resolves the situation. The patient is stabilized after the emergency tracheostomy tube change and placed back on the home ventilator.

Why didn't the suction catheter clear the tracheostomy tube and airway?

**Clinical Pearl**

A mucus plug at the distal tip of a tracheostomy tube may act as a ball valve and a suction catheter may not remove the mucous plug. The suction catheter passes through the mucous plug (Figure 2), but the plug is not removed during return suction. The obstruction continues to occlude the inner lumen of the tracheostomy tube (Figure 3). After each tracheostomy tube change, closely inspect the tube for accumulation of mucus on the tracheostomy tube. To ensure mucous remains thin, evaluate airway hydration by confirming heated humidifier settings and appropriate fluid administration to the patient.

**Case Study 2: Cyanotic Oxygen-Dependent Patient (Oxygen Flow Interruption)**

Mary is a tracheostomized and ventilator-dependent 8-year-old with type 1 spinal muscular atrophy. She receives supplemental oxygen titrated at 1–2 liters per minute through the back of the ventilator to maintain oxygen saturations at 92% or greater. During her routine transport to school,



**Figure 4.** Kinked oxygen tube. Tubing must be free of kinks. Pediatric Home Service, (2019), Roseville, Minnesota.

the pulse oximeter begins to alarm low saturations. On visual assessment, she does not look distressed and lung sounds are normal on auscultation. The ventilator values are within normal limits. During the assessment, she begins to show slight cyanosis.

Which of the following may contribute to this desaturation episode?

- A. Oxygen tubing is kinked
- B. Oxygen tank is empty
- C. Oxygen tube became disconnected from back of ventilator
- D. All the above

**Clinical Pearl**

The answer is “D.” Before transport, ensure the medical equipment is working and necessary supplies are at hand. This includes checking for adequate oxygen in the tank and ensuring that the oxygen regulator is working. Also check that the tubing is correctly connected and free from kinks and other obstructions (Figure 4). Do not rely on other people to prepare safety items.

**Case Study 3: Inflated Cuff With Speaking Valve**

Alecia is a long-time invasively ventilated patient with quadriplegia secondary to a motor vehicle accident as a young child. She is fully alert and directs her own cares. She has an adult, cuffed, single cannula tracheostomy tube. The tracheostomy tube cuff is inflated during sleep and deflated while awake, allowing use of a speaking valve. You are just completing a double shift early in the morning when Alecia is waking for the day. Per her routine, you put the speaking valve on her tracheostomy tube and connect the ventilator circuit to the speaking valve. Alecia immediately shows symptoms of severe distress accompanied by ventilator and pulse oximeter alarms.

How do you respond? What caused this distress?

**Clinical Pearl**

Your first response should be to remove the speaking valve and reconnect the patient to the ventilator. If that does not resolve the situation, use the resuscitation bag to manually ventilate and consider other possibilities. The distress was caused by the cuff, which was still inflated when the speaking valve was placed on the patient (Figure 5). As a result, the patient could not exhale through the upper airway with the cuff inflated and speaking valve in place. A speaking valve only



**Figure 5.** Speaking valve with inflated cuff. A patient cannot exhale through the upper airway with the cuff inflated and speaking valve in place. Pediatric Home Service, (2019), Roseville, Minnesota.

allows airflow thru the tracheostomy tube during inspiration. During expiration, airflow bypasses the tracheostomy tube and is directed through the upper airway and larynx to allow vocalization. Failure to deflate the cuff on a tracheostomy tube before use of a speaking valve causes air trapping and respiratory distress. Always review safety protocols prior to using a speaking valve.

#### Case Study 4: Dislodged Tracheostomy Tube

James is a 12-month-old former 23-week gestation infant with a history of chronic respiratory failure, tracheostomy, and mechanical ventilation. For the past 5 months he has been weaning from respiratory support at home and is currently on low-ventilator settings. He has not started speaking valve trials, nor has he been able to vocalize around his tracheostomy tube. The HCN notes that the patient is agitated with tachypnea, labored breathing, and diaphoresis. For the first time his nurse hears a very faint audible cry and an occasional “whoosh,” but no ventilator alarms are sounding and the patient does not appear cyanotic.

What is your next step in the assessment of this patient?

#### Clinical Pearl

The tracheostomy tube flange, connector, and tracheostomy ties may appear to be in the correct position. However, this can be misleading and it



**Figure 6.** Decannulation exposed. Clothing, dressings, and other items must be moved to visually verify proper tracheostomy tube position. Pediatric Home Service, (2019), Roseville, Minnesota.

is still possible for the shaft of the tracheostomy tube to be displaced (Figure 6). There may be no ventilator alarms if the patient is pressure-ventilated because a kinked tracheostomy tube may create enough resistance to not set off alarms. Full visualization of neck, tracheostomy stoma, and upper chest will exclude decannulation as a cause of respiratory decompensation. Reestablishing the airway should be the priority. If the tracheostomy tube is dislodged and the patient is in distress, immediately reinsert the dislodged tube. Do not waste time searching for, or opening a new sterile tracheostomy tube.

#### Conclusion

Improving outcomes for children on HMV involves recognizing and addressing that inadequate training, improper response, and lack of vigilance are three modifiable factors that contribute to adverse events. To improve safety in the home, a standard routine should be developed starting with a hand-off from the previous caregiver. Patient assessment and equipment checks begin with every shift. Home care nurses must remain attentive throughout the shift focusing on safety checks and frequent patient assessment, especially when troubleshooting alarms and medical devices. Empowering HCNs with adequate training and skill sets that incorporate daily routines may reduce complications and improve outcomes for the ventilator-dependent child. 🏠

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