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## INVASIVE VENTILATORY ASSISTANCE: SUPPLEMENTAL CLINICAL DATA FORM

**Name**

**Summary of the child's main diagnoses**

**Service request**

Given this child's requirements for care as described below and the consensus recommendations of an expert committee representing the four Quebec university hospital centres with a pediatric mission (document available upon request), we recommend                    homecare hours of support per week, including                    hours of care for nighttime surveillance.

**Required care**

Invasive ventilatory assistance

Tracheostomy care

Respiratory care

Preparation and administration of medications

Enteral nutrition

Other care

**Invasive ventilatory assistance**

**Direct child surveillance:** During the times of ventilatory assistance, the child requires direct “eyes on” surveillance by a trained, awake and alert caregiver who is able to assess the child’s respiratory status and perform emergency interventions if required. Outside of the times of ventilatory assistance (if applicable), when awake, the child requires:

access to a trained, skill caregiver who can intervene as required, at all times,  
“eyes on” direct supervision by a trained caregiver, who can intervene as required.

**Implementation of ventilatory assistance:** The use of the ventilator varies according to the health condition of the child and the ventilatory needs of the child. Some children require 24-7 support while others require it during sleep only. The need for ventilatory support may increase during respiratory infections. The implementation of ventilatory support includes the assembly of the ventilatory circuit, the preparation of the humidifier, the starting of the ventilator and the verification that the system is working effectively. The caregiver must also ensure that the tubing is properly placed to prevent water accumulation. If the child also requires oxygen, the caregiver must also install and connect the oxygen to the ventilator. The oxygen installation includes connecting the tube from the ventilator, turning on the oxygen concentrator and adjusting the settings to the required flow rate. Some children may require connection/disconnection from the ventilator several times per day, depending upon their ventilator needs and sleep patterns. Each installation takes an average of 15 to 20 minutes and may be required multiple times per day.

Depending upon this child’s underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care:

**Immediate response to ventilator alarms:** The caregiver must be familiar with the possible alarm situations and be able to respond appropriately. The child’s condition requires rapid assessment; if the child is in respiratory distress, then rapid intervention is also required. During an alarm, the caregiver must:

- Assess the child and the child’s respiratory status
- Take note of the alarm (read the message on the device)
- Intervene as needed to solve the problem which may include:
  - Aspirate tracheobronchial secretions
  - Increase the oxygen concentration provided
  - Perform cough assistance techniques
  - Perform respiratory physiotherapy exercises to improve the respiratory status of the child
  - Change the ventilator circuit

- Connect the spare ventilator in case of device malfunction
- Reset the alarms and ensure that the problem is properly resolved

If there is a change in the ventilatory circuit, then it may be necessary to temporarily ventilate the child manually, using a balloon device; this occurs in children with minimal or no respiratory reserve and usually requires the assistance of a second adult.

If the child continues to be in distress and/or has oxygen desaturation, then the caregiver may need to change the tracheal cannula.

**Oxygen saturation continuous monitoring:** The caregiver must check if the device is connected by looking at the power indicator, verify optimal placement of the oxygen probe, including verification of the readings as correlated with the heart rate (the probe must be re-positioned if the placement is suboptimal) and respond to alarms. The caregiver must be able to respond immediately to all alarms and be prepared to intervene as required. Alarms cannot be ignored; children with these conditions are fragile and can deteriorate rapidly if the early warning signs of problems are not addressed promptly. Caregivers must be able to determine if the alarm is clinically relevant or not (eg, malposition of the oxygen saturation probe).

**Preparation for transport or other outings:** The preparation time for an out-of-home outing depends upon the complexity of the child's care (number of hours of ventilatory assistance, ability to breathe autonomously or not, oxygen need, amount of respiratory secretions, etc.). All children must have a travel bag containing a manual ventilator balloon device, spare tracheostomy cannula, a ventilatory reserve circuit and all supplies required for the aspiration of tracheobronchial secretions, including a manual back up device. Equipment required during outings includes: a ventilator, batteries for the ventilator, a suction device, an oxygen cylinder and a device for cough assistance if required. If the child has minimal autonomy for breathing, then it is strongly recommended that a back-up ventilator also be available during outings. The time required to prepare for outings can vary from 15 to 30 minutes, depending upon the complexity of care required by the child.

**External battery:** Ventilators may operate with different types of external batteries. The caregiver must ensure that one or more external batteries are on hand and fully charged at all times. The caregiver must verify the battery function during outings. The time required for this preparation and organization will depend upon the degree of the child's ability to breathe autonomously and can vary from 10 to 15 minutes/day.

**Troubleshooting:** The parents have been taught how to evaluate and solve common problems associated with ventilatory care.

### Tracheostomy care

**Tracheostomy care** includes skin care around the tracheostomy, checking and changing the tracheostomy ties, changing the tracheostomy cannula as required and verification of the tracheal balloon (if applicable).

**Skin care around the tracheostomy:** The integrity of the skin around the tracheostomy, under the flanges of the tracheal cannula and underneath the tracheostomy ties must be evaluated daily for signs of inflammation. The skin must be kept clean and dry. Children who have abundant respiratory secretions may also require placement of a compress around the tracheostomy site to keep the skin dry. This compress must be changed if wet or soiled. The skin around the tracheostomy and under the flanges of

the tracheal cannula must be cleaned 1 to 2 times per day as needed or more frequently if there are abundant secretions. The time needed for this care is approximately 10 minutes per cleaning, with a range of 2 to 20 minutes.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/tracheostoma-skin-care-changing-the-tracheostomy-dressing-changing-the-inner-cannula-of-a-tracheostomy-if-present/>

**Changing the tracheostomy ties:** The tracheostomy ties must be verified for position and tightness daily. The ties must be changed at least 2 times per week and more often if they become wet or soiled. The time required for this care is approximately 10 to 20 minutes/change.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/changing-tracheostomy-ties/>

**Aspiration of tracheobronchial secretions during periods of ventilation:** In order to aspirate tracheobronchial secretions, the ventilated child must be briefly disconnected from the ventilator. Before or after aspiration of secretions, some children may require increased oxygen, increased ventilation or hyperinflation with a manual balloon, so that they can safely tolerate the suctioning procedure. Following each aspiration or at the end of the aspiration episode, the child is then reconnected to the ventilator. Each episode of tracheobronchial aspiration of secretions lasts, on average 5 to 10 minutes and is recommended as a minimum 2 times per day; the frequency of aspiration may increase during respiratory infections and may be necessary several times per day, including during the daytime and nighttime, depending upon the size of the child's airways and the general state of the child.

**Instillation of saline drops (NaCl 0.9%)** using a ready to use sterile vial is sometimes necessary prior to aspiration of secretions, especially if the tracheobronchial secretions are very thick. Instillation of saline drops is performed as needed, adding approximately 2 to 5 minutes to each episode of aspiration of secretions.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/aspiration-of-secretions/>

**Aspiration of tracheobronchial secretions during periods off of mechanical ventilation:** The aspiration of tracheobronchial secretions during periods where the child is not mechanically ventilation takes approximately 3 to 5 minutes per episode of aspiration, at a minimum frequency of 2 times per day; the frequency of aspiration may increase during respiratory infections and may be necessary several times per day, including during the daytime and nighttime, depending upon the size of the child's airways and the general state of the child.

**Instillation of saline drops (NaCl 0.9%)** using a ready to use sterile vial is sometimes necessary prior to aspiration of secretions, especially if the tracheobronchial secretions are very thick. Instillation of saline drops is performed as needed, adding approximately 2 to 5 minutes to each episode of aspiration of secretions.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/aspiration-of-secretions/>

**Changing the tracheal cannula:** The tracheostomy cannula must be changed at least once per month and more often as required, especially during respiratory infections, with accumulation of secretions or if there is a sudden obstruction of the cannula. The time required is on average 15 to 20 minutes/change. It is strongly recommended to have two trained caregivers present during the change of the tracheal cannula.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 2 people
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/changing-of-a-simple-tracheal-cannula/>

**Troubleshooting:** The parents have been taught how to evaluate and solve common problems associated with tracheostomy care and invasive ventilation.

### Respiratory care

**Aspiration of oral/nasopharyngeal secretions:** The frequency of required aspiration depends upon the child's ability to effectively clear secretions autonomously. Aspiration of oral/nasopharyngeal secretions included: preparation of all materials, verifying the function of the suction device, positioning the child appropriately, completing the suction procedure (see methods of care). The frequency of required suctioning may increase during respiratory infections. Each episode of oral/nasopharyngeal suctioning takes, on average, 10 minutes/episode.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/aspiration-of-secretions/aspiration-of-oral-secretions/> and <https://complexcareathomeforchildren.com/respiratory-support/aspiration-of-secretions/nasopharyngeal-aspiration-of-secretions/>

**Cough assist care:** Techniques to assist /augment the child's cough may be required daily and will be required more often during respiratory infections. These techniques may be used alone or along with:

**Techniques to aid expiration:** Children who have sufficient inspiratory force can use manual cough techniques. This includes positioning the child for comfort and then performing the recommended technique (abdominal thrusts, chest compressions or lateral chest compressions); repeating the technique until the child is able to cough or becomes tired. These interventions are required on average 2 to 4 times per day, with each session lasting approximately 15 minutes.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/cough-assist-care/expiratory-aid/>

**Techniques to aid inspiration: Alveolar recruitment** is an inspiratory assistance technique that decreases chest wall rigidity and helps clear the airway. The technique should be performed 2 to 4 times per day and involves placing a face mask or mouthpiece on the child's face, compressing the modified ventilation balloon 3 to 5 times consecutively, and then removing the mask or mouthpiece to allow the child to exhale and cough. The maneuver is repeated 5 to 8 times, with each session lasting approximately 10 minutes.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/cough-assist-care/inspiratory-aid/>

**Techniques to aid inspiration and expiration:** The Cough Assist device is used to mobilize bronchial secretions both as a part of regular respiratory care to prevent respiratory infections and retention of secretions and at an increased frequency during respiratory infections. This technique is recommended 2 to 4 times per day, and more often, if needed, according to the recommendations of the healthcare team. The technique includes: starting the Cough Assist device, installing a face mask or mouthpiece which is connected to the device, running the device to perform 3 to 5 maneuvers per inspiration-expiration cycle, taking a short break and then repeating the cycle 4 to 6 times. If necessary, the caregiver aspirates secretions during or after the cough assist treatment. Each treatment lasts, on average 10 to 20 minutes; the duration can vary widely depending upon the child's need for aspiration of secretions, degree of cooperation, etc.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:

- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: <https://complexcareathomeforchildren.com/respiratory-support/cough-assist-care/inspiratory-expiratory-aid/>

### Preparation and administration of medications

**Medications by mouth or by feeding tube:** The time required for medication preparation depends on the number and type of medications.

Depending upon this child's underlying conditions, we estimate:

- Number of medications:
- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)

The time required for medication administration also depends upon the child's age and ability to cooperate with the care. If the medications are given by a feeding tube, the parent must flush the tube before and after each medication administration. The time required depends upon the number of medications required. On average, medication administration via the feeding tube takes 5 to 10 minutes/administration.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care:

**Inhaled medications:** Some children may require inhaled medications, for example, to treat airway inflammation. Medications may be administered by metered dose inhaler or via a small volume nebulizer.



**Administration of medication via metered dose inhaler via the ventilatory circuit:** If given while a child is being mechanically ventilated, the medication is administered with a device through the ventilatory circuit. If the medication is given when the child is not mechanically ventilated, then the medication is administered with a spacer device (eg, AeroChamber®) placed on the connector of the tracheal cannula. The medication is released by pumping the metered dose inhaler. On average, administration of medication via metered dose inhaler takes 5 to 10 minutes/administration.

Depending upon this child's underlying conditions, we estimate:

- Number of medications:
- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: [https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/administration-of-medication-via-tracheostomy/#m\\_1\\_2](https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/administration-of-medication-via-tracheostomy/#m_1_2)

**Administration of medication via small volume nebulizer via the ventilatory circuit:** The parent must prepare the medication, add the medication to the nebulizer, prepare the delivery system (compressor), connect the system to the ventilatory circuit and administer the medication. If the medication is given when the child is not mechanically ventilated, the nebulizer is attached directly to a tracheal collar placed over the tracheostomy. Each administration of medication using this method takes on average 25 minutes.

Depending upon this child's underlying conditions, we estimate:

- Number of medications:
- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care: [https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/administration-of-medication-via-tracheostomy/#m\\_1\\_1](https://complexcareathomeforchildren.com/respiratory-support/tracheostomy-care/administration-of-medication-via-tracheostomy/#m_1_1)

**Enteral nutrition**

**Direct child surveillance:** The parent must supervise the child (especially young children or those with neurological impairment) to ensure that the child does not dislodge the feeding tube. During enteral feeds, the child should be under direct supervision.

**Care of the feeding tube:** The integrity of the skin around the feeding tube must be assessed daily. The skin should be clean, dry and not irritated. The site should be cleaned, on average 1 to 2 times per day and more often if required. To keep the skin dry, a compress may be placed around the feeding tube; this should be changed if wet or soiled. If the child has a nasal tube, the parent should ensure that the dressing that secures the tube in place is intact and changed as needed. Care of the skin takes, on average, 5 to 15 minutes per day.

Depending upon this child's underlying conditions, we estimate:

- Type of feeding tube:
- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 person (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care:

The placement of the feeding tube should be verified after inserting the tube, before each use and as needed.

The feeding tube should be flushed at least twice per day if not in use, before and after each feed, before and after each medication administration and at least once every 4 hours for continuous feeds.

If the feeding tube is a button, the parent must connect an extension tube for administration. If the button has an internal balloon, the volume of water must be verified at least once weekly, as per the attending healthcare team.

**Preparation of the enteral feed:** There are many different types of nutritional formulas. Some are "ready to feed" and others require preparation. Some children require special additives or medications, which increases the complexity of the preparation and the time required. On average, preparation of enteral feeds takes 20-30 minutes/day.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 person

**Feeding administration:** Enteral feeds may be continuous, intermittent or a combination of continuous and intermittent via syringe (manual delivery), by gravity or by pump. The time required for preparing the feeding administration depends upon the method used. The feeding tube must be flushed before and after each feed and at least every 4 hours for continuous feeds. Most often, enteral feeds are given intermittently during the day over a one hour period and continuously at night.

Depending upon this child's underlying conditions, we estimate:

- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 person (a 2<sup>nd</sup> person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care:

**Respond to the child's needs at night:** If the child is receiving continuous feeds overnight, the parent must refill the feeding bag every 4 hours, flush the feeding tube every 4 hours, and respond to pump alarms. In the event of a pump alarm, the parent must determine the cause and solve the issue.

**Troubleshooting:** The parents have been taught how to evaluate and solve common problems with enteral feeding administration at home.

### Care and maintenance of respiratory equipment

We estimate the time required:

#### Ventilator maintenance:

- Daily: Change the water in the humidifier tank and rinse tank (5 min)
- Weekly:
  - Clean tubing and the humidifier (40 minutes)
  - Check/clean/change the ventilator filters (5 minutes)
  - Clean/change the tracheal cannula adapter if soiled (5 minutes) or more often if required

#### Cleaning the suction device:

- Daily: Empty the collection canister and rinse (5 minutes)
- Weekly: Clean the collection canister (10 to 20 minutes)
- Monthly: Change the filter and suction tubing (10 minutes)

**Maintenance of the Cough Assist device:**

- Weekly: Clean the tubing and mask/mouthpiece (included in the 40 minutes of ventilator maintenance)
- Monthly: Change the antibacterial filter and check the grey filter (5 minutes)

**Order supplies** (call to suppliers)

- Aspiration of tracheobronchial secretions (3 times/year) (15 minutes)
- Ventilatory assistance (1 to 2 times/year) (15 minutes)
- Oxygen therapy (6 times/year) (15 minutes)

**Other care**

Preparation of daily solutions (eg, boiled water). Average time required: 15 minutes/day

Cleaning of gavage tubing. On average: 30 minutes/day

Inventory of supplies, re-ordering as required. On average: 60 minutes/month

**Signature:**

**Date:**



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### INVASIVE VENTILATORY ASSISTANCE: SUPPLEMENTAL CLINICAL DATA FORM

Name

Care Planning Schedule – To be completed by the professional

|                | Ventilatory assistance care | Tracheostomy care | Respiratory care | Preparation and administration of medications | Enteral nutrition | Other care |
|----------------|-----------------------------|-------------------|------------------|---|-------------------|------------|
| 00:00<br>06:00 |                             |                   |                  |   |                   |            |
| 06:00<br>12:00 |                             |                   |                  |   |                   |            |
| 12:00<br>18:00 |                             |                   |                  |   |                   |            |
| 18:00<br>24:00 |                             |                   |                  |   |                   |            |