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NON INVASIVE VENTILATORY ASSISTANCE: SUPPLEMENTAL CLINICAL DATA FORM

Name

Summary of the child's main diagnoses

Requested support

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

- ☐ Non invasive ventilatory assistance
- ☐ Respiratory care
- ☐ Preparation and administration of medications
- ☐ Enteral nutrition
- ☐ Other care

☐ **Non invasive ventilatory assistance**

☐ **Direct child surveillance:** For certain children, an interruption in ventilation, during the day or night, may put the child's life in danger. In this situation, 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 the times of ventilatory assistance (if applicable), the child requires the supervision of an adult who is able to assess the child's respiratory status (including the degree of bronchial congestion and respiratory fatigue) and to start the ventilatory assistance if required.

☐ **Implementation of non-invasive ventilatory assistance** ☐ **BiPAP or** ☐ **CPAP:** The use of non-invasive ventilatory assistance 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. Implementation of non invasive ventilatory assistance includes: assembly of the ventilatory circuit, the preparation of the humidifier, verification that the system is in working order, connection of the face mask or similar device, starting the ventilatory assistance device and verifying correct positioning of the tubing to prevent accumulation of water. If the child requires oxygen, the caregiver must also install and connect the oxygen to the device. The oxygen installation includes connecting the tube from the device, turning on the oxygen concentrator and adjusting the settings to the required flow rate. Some children may require connection/ disconnection from the device 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 2nd person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care:

☐ **Immediate response to ventilatory assistance device 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:
  - Reposition the mask if there is a leak
  - Aspirate secretions if required, implement cough assist techniques
  - Reconnect any disconnected tubing
  - Change the ventilatory circuit

- Connect the device to an external battery in the case of power failure
- 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 temporary ventilate the child manually, using a ventilatory bag; this occurs in children with minimal or no respiratory reserve and usually requires the assistance of a second adult.

☐ **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 ventilatory bag, a ventilatory reserve circuit and all supplies required for the aspiration of secretions, including a manual back up device. Equipment required during outings includes: a ventilatory assistance device, batteries for the device, 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 ventilatory assistance device 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:** Ventilatory assistance device 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.

☐ **Respond to the child's needs at night:** The parent must sometimes get up several times a night to meet the needs of the child. On average, the parent needs to get up 2 to 3 times/night to reposition the child comfortably, respond to alarms from the ventilation device, the saturation monitor and/or adjust the ventilatory mask (to prevent leaks/skin breakdown), assist the child for toileting needs, etc.

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

☐ 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 2nd 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 2nd 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 ventilatory bag 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 2nd 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 2nd 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 2nd 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:

- Number of medications:
- Frequency of care:
- Total time/day:
- Number of caregivers required: 1 to 2 people (a 2nd 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:** The medication in the metered dose inhaler is administered with a device through the ventilatory circuit. Outside the periods of ventilation, the medication is delivered using a spacer device with a mask placed over the child's mouth/nose. The medication is vaporized by pressing the cartridge. Each administration lasts, on average 5 to 10 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 2nd person may be needed if the child is young and/or unable to stay still during care)

- Recommended method of care:

☐ **Administration of medications via a small volume nebulizer via the ventilatory circuit:** The parent must prepare the medication, add the medication in the nebulizer, prepare the delivery system (compressor), connect the system to the ventilatory circuit and administer the medication. If not ventilated, the nebulizer is attached directly to a mask which is placed over the child's mouth/nose. 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 2nd person may be needed if the child is young and/or unable to stay still during care)
- Recommended method of care:

☐ **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 reviewed 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 2nd 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 2nd 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.

☐ **Other care**
☐ Physiotherapy: 1 to 2 times/day; each session on average 20 to 30 minutes
☐ Transfers and repositioning:
☐ 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
☐ Maintenance of equipment and cleaning of devices. On average 25 minutes/day

Signature: **Date:**

NON INVASIVE VENTILATORY ASSISTANCE: SUPPLEMENTAL CLINICAL DATA FORM

Name
Care Planning Schedule – To be completed by the professional

	Implementation of Non invasive ventilatory care	Respiratory care	Preparation and administration of medications	Enteral nutrition	Other care
00:00 06:00					
06:00 12:00					
12:00 18:00					
18:00 24:00					