



Recommendations for home care support
Recommendations of the experts from Quebec's University Pediatric Centres

Parenteral nutrition
Peritoneal dialysis
Tracheostomy care
Non-invasive ventilatory assistance with BiPAP
Non-invasive ventilatory assistance with CPAP
Invasive ventilatory assistance by tracheostomy

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With the collaboration of the National Program for Home Ventilatory Assistance (NPHVA)

Finalised June 2017

General comments:

- These recommendations were developed by expert panels for each category of care defined in this document. They were established after reviewing the medical literature to date (available upon request). There is little or no evidence or formal recommendations from learned societies on supporting children with complex home care needs. Therefore, these recommendations were prepared primarily by consensus, based on clinical experience and questionnaires on the amount of care needed, completed by families (publication in preparation). For children on ventilatory assistance, this document draws directly from the *Canadian Thoracic Society's* recommendations released in 2017¹.
- This document describes:
 - o different levels of intensity for each category of care. The description of care proposed for each of these levels is not exhaustive. Usually, the patient moves gradually from one level of intensity to the next, so support should increase or decrease over time.
 - o “typical” care hours recommended for specific care (average time required to provide care). **It does not take into account the significant co-morbidities that quite often exist with these children and their families and which have a major impact on the burden of care. In these cases, the allocation of care hours will need to be increased on an individual basis.**
 - o the average recommended care hours for the home. In some cases, **these care hours will need to be increased to take into account factors other than medical factors** (see note at the bottom of the tables).
- In this document, the time required to provide the different types of care was validated on the basis of a questionnaire completed by the parents of the children concerned (this questionnaire was administered in 2015-2016 for parenteral nutrition, peritoneal dialysis and tracheostomy care and in 2016-2017 for BIPAP and CPAP).
- This document was drawn with the following principles:
 - o for daytime care, approximately 50% of the care is provided by the family itself and assistance is required for the other 50%; “daytime care” includes not only direct care but also supervision by a trained person. If constant supervision is required during the day, some respite must be provided to families.
 - o for night-time care, assistance is required for 50-100% of the care to be given, depending on the intensity of the care. Most often, the “basic intensity” category and in a number of cases the “moderate intensity” category do not require overnight care.
- It is important to note that it is often the case that the child is not able to participate in his or her care and that two people, not just one, are needed to provide the required care. This increases the burden of the task.
- For each case, the need for home support should be reassessed at least annually, or more often if deemed necessary or appropriate.

¹ Amin R, et al. Pediatric home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline executive summary. *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine*. 2017;1:7-36.

1. PARENTERAL NUTRITION ^{a, b}			
Type of care	Needs of the child	Average time required to provide care related to parenteral nutrition (including direct care and monitoring)	Recommended allocation on average for the home (as an indication)
1.1 Basic intensity	<ul style="list-style-type: none"> - Daily connection and disconnection of the catheter by the person in charge of care. - The child understands the risks associated with the presence of the catheter and can help with care. The child is continent. - The child feeds himself by mouth. Enteral feeds (via NG or GT) may be required but require minimal assistance or care. 	1.5 hour/day OR 10.5 hours/week	0.7 hour/day OR 5 hours/week
1.2 Moderate intensity	<ul style="list-style-type: none"> - Daily connection and disconnection of the catheter by the person in charge of care. - The child does not understand the risks associated with the presence of the catheter and cannot help with care. The child requires direct supervision during the day. - The child is continent. - The child often needs gavages (enteral nutrition via NG or GT). May feed partially by mouth, but meals are often of very long duration. 	3-4 hours/day OR 21-28 hours/week PLUS: direct monitoring at all times of the day	1.5-2 hours/day OR 10-14 hours/week
1.3 High intensity	<ul style="list-style-type: none"> - Daily connection and disconnection of the catheter by the person in charge of care. - The child does not understand the risks associated with the presence of the catheter and cannot help with care. The child requires direct supervision during the day. - The child is incontinent. - The caregiver has to get up at least twice at night because of “overflowing” stools that require not only a diaper change but often also a change of clothing and bedding. - The child often needs gavages (enteral nutrition via NG or GT). May feed partially by mouth, but meals are often of very long duration. For gavages, may need special formulas that are not ready to use and take a long time to prepare. 	4 hours/day OR 28 hours/week PLUS: direct monitoring at all times of the day PLUS: several night-time interventions	38 hours/week (i.e., 2 hours/day, 4 days/week for the day, and 3 nights/week at 10 hours/day)

^a **Parenteral nutrition at home for children (PN): key elements associated with increased parenting tasks:**

- First year at home with the PN.
- Significant extra-intestinal comorbidity.
- No collaborative care on the part of the child (more than one person is then required to manipulate the catheter).
- Child unaware of potential risks related to PN (e.g., catheter outlet).
- Associated eating disorders (extends the time spent on PO meals).
- Urinary incontinence.
- Fecal incontinence.
- Significant number of stools at night in incontinent children.

- Continuous enteral feeds over several hours.
- Large volume/kg of PN in incontinent children (the greater the volume of solution administered, the greater the urine output and the more frequent the number of diaper changes).
- Daily duration of the PN.
- Catheter length (the shorter the catheter, the greater the risk of accidental dislodgement).
- Number of medications to be given.
- Intravenous medication administration.
- Enteral formula changes every four (4) hours for formulas not ready to use (some specialized formulas require additional preparation).

^bSuggested non-medical criteria for increasing the recommended allowance (see right-hand column) (non-exhaustive list):

- 1) Single-parent family OR family at risk of breakdown (as identified by multidisciplinary assessment).
- 2) Siblings under 3 years of age and not attending an early childhood center (or other child care system).
- 3) Physical or mental health problems in the parent or caregiver.
- 4) Siblings with significant physical or mental disability.
- 5) Child protection risks evident.

2. PERITONEAL DIALYSIS ^{a, b}			
Type of care	Needs of the child	Average time required to provide care related to peritoneal dialysis (including direct care and monitoring)	Recommended allocation on average for the home (as an indication)
2.1 Basic intensity	<ul style="list-style-type: none"> - Preparation of the dialysis bag with addition of medication as needed, sterile daily connection and disconnection of the dialysis bag by the person in charge of care. - Preparation and administration of medications by oral, subcutaneous or intraperitoneal route (as appropriate). - Weighing daily and measuring blood pressure twice a day by the person in charge of care. - The child understands the risks associated with the presence of the dialysis catheter and can help with care. - The child eats by mouth. 	<p>2 hours/day</p> <p>OR</p> <p>14 hours/week</p> <p>PLUS: night-time interventions required in some children</p>	<p>1 hour/day</p> <p>OR</p> <p>7 hours/week</p> <p>NB: Given night-time interventions, 1 night/week (10 additional hours) may be necessary for some children</p>
2.2 Moderate intensity	<ul style="list-style-type: none"> - Preparation of the dialysis bag with addition of medication as needed, sterile daily connection and disconnection of the dialysis bag by the person in charge of care. - Preparation and administration of medications by oral, subcutaneous or intraperitoneal route (as appropriate). - Weighing daily and measuring blood pressure twice a day by the person in charge of care. - The child does not understand the risks associated with the presence of the dialysis catheter and cannot help with care. - Can feed by mouth but meals are often very long. Oral medication is often difficult to take (nausea, vomiting) because of digestive intolerance related to chronic renal failure. - The caregiver must get up at least twice at night to respond to alarms. 	<p>3 hours/day</p> <p>OR</p> <p>21 hours/week</p> <p>PLUS: several night-time interventions</p>	<p>27.5 hours/week (i.e., 1.5 hour/day 5 days/week for the day, and 2 nights/week at 10 hours/day)</p>
2.3 High intensity	<ul style="list-style-type: none"> - Preparation of the dialysis bag with addition of medication as needed, sterile daily connection and disconnection of the dialysis bag by the person in charge of care. - Preparation and administration of medications by oral, subcutaneous or intraperitoneal route (as appropriate). - Weighing daily and measuring blood pressure twice a day by the person in charge of care. - The child does not understand the risks associated with the presence of the dialysis catheter and cannot help with care. - The child requires enteral nutrition via NG or GT. May feed partially by mouth, but meals are often of very long duration. Giving oral or enteral medication is often difficult (nausea, vomiting) because of digestive intolerance related to chronic kidney failure. - The caregiver must get up at least twice at night to respond to alarms. 	<p>4 hours/day</p> <p>OR</p> <p>28 hours/week</p> <p>PLUS: several night-time interventions</p>	<p>30 hours/week (i.e., 2 hours/day 5 days/week for the day, and 2 nights/week at 10 hours/day)</p>

^a Peritoneal dialysis at home for children: key elements associated with increased parenting tasks:

- Need for enteral nutrition by gavages (gavages are often poorly tolerated in children with kidney failure, prolonging the time required for administration).
- Children who move around a lot at night, setting off alarms and requiring intervention each time (especially in children under 4-5 years of age).
- Administration of medication by gastric tube (often longer than oral, can make the fluid balance more precarious if fluids have to be injected to give the medication).

- Significant extra-renal co-morbidity (present in about 50% of cases).
- Home away from the hospital center that provides follow-up; distance to travel for appointments, if they are close together; takes up a lot of time for other tasks (e.g., preparation of medication, feeding, dialysis).

^bSuggested non-medical criteria for increasing the recommended allowance (see right-hand column) (non-exhaustive list):

- 1) Single-parent family OR family at risk of breakdown (as identified by multidisciplinary assessment).
- 2) Siblings under 3 years of age and not attending an early childhood center (or other child care system).
- 3) Physical or mental health problems in the parent or caregiver.
- 4) Siblings with significant physical or mental disability.
- 5) Child protection risks evident.

3. TRACHEOSTOMY CARE ^{a, b}			
Type of care	Needs of the child	Average time required to provide care related to tracheostomy (including direct care and monitoring)	Recommended allocation on average for the home (as an indication)
3.1 Basic intensity	<ul style="list-style-type: none"> - The child can clear own secretions with functional cough, so regular aspiration of secretions not required, apart from during acute respiratory tract infections. - The child can help with care or provide care on his or her own. - The child understands the risks associated with the presence of the tracheostomy. The child can call for help if needed. - May need pulse oximeter monitoring under certain circumstances. - The child eats by mouth. Enteral feeds (via NG or GT) may be required but require minimal assistance or care. - The child requires access at all times to a trained person who is able to intervene in the event of respiratory distress (e.g., blocked or dislodged tracheostomy) (if the child is in school, there must be a person on site at the school who is able to intervene appropriately). 	Approximately 30 min per day	—
3.2 Moderate intensity	<p>The child meets most or all of the following characteristics:</p> <ul style="list-style-type: none"> - Although the child is able to partially clear own secretions with a functional cough, regular aspiration of secretions is required at least twice a day, and more often during acute respiratory tract infections. - The child does not or minimally recognizes the risks associated with the presence of the tracheostomy. The child may be able to call for help if needed, although this is not entirely reliable. - The child needs to be cared for 24 hours a day by a trained caregiver who can assess respiratory status and intervene in case of complications (if the child is in school, there must be a person on site at the school who is able to intervene appropriately). - During the day, the child requires direct supervision (“eyes-on”) and during sleep (naps and night-time), the child is usually monitored by a pulse oximeter. - The caregiver may have to get up at night because of the need for endotracheal suctioning or to respond to alarms from the saturometer, but these interventions are infrequent outside of episodes of respiratory deterioration (e.g., pneumonia, tracheitis). - If going to school, the child needs an attendant (a trained caregiver who can assess respiratory status and intervene in case of complications). - Enteral feeds (via NG or GT) may be required but require minimal assistance or care. 	<p>1-2 hours/day</p> <p>OR</p> <p>7-14 hours/week</p> <p>PLUS: on waking up, direct supervision (“eyes-on”) at all times</p> <p>PLUS: night-time interventions often required in case of respiratory deterioration (usually short-term only)</p>	<p>10-15 hours/week during the day</p> <p>PLUS: transient night-time support is often necessary in case of respiratory deterioration</p>
3.3 High intensity^c	<p>The child meets most or all of the following characteristics:</p> <ul style="list-style-type: none"> - The child requires aspiration of secretions at least 4-6 times a day, and more often in case of respiratory infection. - The child does not or minimally recognizes the risks associated with the presence of the tracheostomy. The child is not able to help provide care. - The child is not able to call for help if needed. 	<p>1.5-2.5 hours/day</p> <p>OR</p> <p>10-18 hours/week</p>	<p>58-60 hours/week (i.e., 8-10 hours/week during the day and 5 nights/week at 10 hours/day)</p>

	<ul style="list-style-type: none"> - The child needs to be cared for 24 hours a day by a trained caregiver who can assess respiratory status and intervene in case of complications (if the child is in school, there must be a person on site at the school who is able to intervene appropriately). - During the day, the child requires direct supervision (“eyes-on”). - During sleep (naps and night), the child must be monitored by: <ol style="list-style-type: none"> 1) A continuous pulse oximeter (most frequent situation); the caregiver must get up often at night because of the need for endotracheal suctioning or to respond to alarms from the pulse oximeter. 2) <i>In addition, if the upper airway is severely compromised</i>, the child requires “eyes-on” bedside surveillance in addition to pulse oximeter monitoring^d. - The child requires enteral nutrition via NG or GT. May feed partially by mouth, but meals are often of very long duration. 	<p>PLUS: on waking up, direct supervision (“eyes-on”) at all times</p> <p>PLUS: several night-time interventions 7 days/7 (long term)</p> <p>PLUS (in children with severely compromised airway): continuous monitoring during sleep by an awake trained caregiver at the bedside</p>	<p><i>In case of highly compromised airway:</i> 78-80 hours/week (i.e., 8-10 hours/week during the day, plus 7 nights/week at 10 hours/day)</p>
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^a **Tracheostomy care at home for children: key elements associated with increased parenting tasks:**

- Little or no cooperation from the child (due to chronological or developmental age).
- Intensity of the need for endotracheal suctioning.
- Need for enteral nutrition (gavages) or associated eating disorder.
- Size of the child (the risk of decanulation and cannula obstruction is greater in small children, who must therefore be monitored more closely).
- Requires particularly close observation due to highly compromised airways (see below).
- Significant co-morbidity (e.g., neurological impairment, oxygen-dependent lung disease).

^b **Suggested non-medical criteria for increasing the recommended allowance (see right-hand column) (non-exhaustive list):**

- 1) Single parent family OR Physical or mental health problems in the parent or caregiver.
- 2) Siblings under 3 years of age and not attending an early childhood center (or other child care system).
- 3) Siblings with significant physical or mental disability.
- 4) Child protection considerations at play OR Family at risk of disruption (as identified by multidisciplinary assessment).

^c Children under 2 years of age are usually in this category.

^d **The upper airway is considered to be highly compromised (critical airway) if:**

- 1) accidental decanulation or obstruction of the endotracheal cannula causes immediate severe hypoxemia;
- 2) OR a person with special expertise is required to reinsert the tracheotomy (e.g., non-standard cannula, complex reconstruction) (in this case, the child must be kept under supervision in the hospital).

This is especially true for very young children who are already in the “High Intensity” category, given their high need for aspiration of secretions and their inability to collaborate in care. Exceptionally, a child otherwise in the “Moderate Intensity” group (less need for suctioning and some understanding of the risks) may have a severely compromised upper airway^c; in such a case, pulse oximeter monitoring during all sleep periods may be necessary, and the caregiver may have to get up several times during the night to respond to alarms. In such cases, the requested allowance should be adjusted accordingly.

4. NON-INVASIVE VENTILATORY ASSISTANCE WITH BIPAP ^{a, b}			
Type of care	Needs of the child	Average time required to provide respiratory care (including direct care and monitoring)	Recommended allocation on average for the home (as an indication)
4.1 Basic intensity	<ul style="list-style-type: none"> - The child requires ventilatory assistance at night only. - The child is able to put on or remove the BiPap interface independently. The child can call for help if needed. - The child can safely tolerate a temporary interruption of ventilatory assistance. - The child is able to clear own secretions with effective cough. - The child can assist with care. - The child understands the risks associated with the use of non-invasive ventilatory assistance. - The child usually tolerates respiratory infections fairly well, without increasing the need for ventilation. - The child eats by mouth. Enteral feeds (via NG or GT) are not usually required. 	Approximately 30 min per day	—
4.2 Moderate intensity	<ul style="list-style-type: none"> - The child is ventilated at night and may need to be ventilated during the day. However, even during periods of ventilatory assistance, the child may tolerate a short-term interruption of ventilation (e.g., less than a few hours). - The child needs cough assist techniques for preventive or therapeutic purposes. - The child may need transient nasopharyngeal suctioning, especially in the case of a respiratory infection. - In the case of a respiratory infection, additional hours of ventilatory assistance and cough assist are usually required to facilitate clearance of secretions and prevention of respiratory distress. <p>In addition, the following characteristics are often observed:</p> <ul style="list-style-type: none"> - The child needs help installing and adjusting the interface (in pre-school children, the interface often needs to be replaced a few times during the night). - The child may have difficulty communicating or to call for help when needed. - During periods of ventilatory assistance, the child is monitored with respirator alarms (which are triggered if there is a leak) and, in some cases, with a pulse oximeter. - The child must be supervised at all times by a trained person: <ol style="list-style-type: none"> 1) capable of assessing the child's respiratory condition, including the need for aspiration of secretions; 2) able to start ventilatory assistance earlier than expected if necessary; and 3) during periods of ventilation, able to intervene in case of complications or if an alarm sounds. - The child often requires enteral nutrition via NG or GT. May feed partially by mouth, but meals are often of very long duration. - If going to school, the child needs an attendant (a trained caregiver who can assess respiratory status and intervene in case of complications) OR the child attends a specialized school adapted to needs with staff who can intervene as needed. 	<p>1.5-2.5 hours/day</p> <p>OR 10-18 hours/week</p> <p>PLUS: on waking up, direct supervision (“eyes-on”) at all times, by a trained caregiver who is able to intervene as required</p> <p>PLUS: night-time interventions usually necessary even during periods of stability (interface replacement, responses to alarms, etc.).</p> <p>PLUS: additional night-time interventions often necessary in case of acute respiratory infections and expected respiratory deterioration</p>	<p>10-15 hours/week</p> <p>PLUS: Transient night-time support for a few days or weeks is often necessary during respiratory tract infections when the frequency of aspiration of secretions is expected to increase</p>

<p>4.3 High intensity</p>	<ul style="list-style-type: none"> - The child is ventilated at night and during naps. In many cases, the child also needs ventilatory assistance during the day when awake. - The child often does not tolerate even a brief interruption of ventilatory assistance (a child who is completely dependent on ventilation does not tolerate any interruption of ventilation). - Respiratory infections increase respiratory distress and often increase the need for ventilatory assistance up to 24 hours a day. - The child requires preventive or therapeutic cough assist techniques. - The child requires nasopharyngeal suctioning at least twice a day, even when well. <p>In addition, the following characteristics are often observed:</p> <ul style="list-style-type: none"> - The child needs help installing and adjusting the interface (in pre-school children, the interface often needs to be replaced a few times during the night). - The child may have difficulty communicating or to call for help when needed. - The child requires enteral nutrition via NG or GT. May feed partially by mouth, but meals are often of very long duration. <p><i>During periods of ventilatory assistance:</i></p> <ol style="list-style-type: none"> 1) The child must be monitored with a pulse oximeter and respirator alarms (these will sound in the event of a leak) and during these periods the child should be under the supervision of a caregiver who can intervene in the event of complications or if an alarm sounds. 2) In addition, in cases of complete dependence on ventilatory assistance, the child must be supervised by a skilled and trained caregiver who is awake at his bedside and able to intervene in the event of complications (a life-threatening complication can occur at any time). <p><i>Outside periods of ventilatory assistance,</i> the child must be supervised by a caregiver who is able to assess the child's respiratory status, including bronchial congestion, and if necessary be able to start ventilatory assistance earlier than planned.</p> <ul style="list-style-type: none"> - The child needs frequent positioning. - If the child is attending school, a trained caregiver is required who is able to start ventilatory assistance as needed and intervene in case of deterioration OR the child is attending a specialized school adapted to these needs with skilled personnel who are able to intervene as needed. 	<p>3.0-4.5 hours/day</p> <p>OR</p> <p>21-32 hours/week</p> <p>PLUS: on waking up, direct supervision ("eyes-on") at all times, by a trained caregiver who is able to intervene as required</p> <p>PLUS: several night-time interventions 7 days a week</p> <p>PLUS (in children who are completely dependent on the respirator): continuous monitoring during sleep by an awake trained caregiver at the bedside during ventilatory assistance episodes</p>	<p>60-65 hours/week (i.e., 10-15 hours/week during the day and 5 nights/week at 10 hours/day)</p> <p><i>In case of complete dependence on the respirator</i> 80-95 hours/week (i.e., 10-15 hours/week during the day, plus 7 nights/week at 10 hours/day)</p>
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^a **Key elements associated with increased parental work for children with BIPAP:**

- Respiratory infections (increased secretions, ventilation hours often increased).
- Little or no cooperation from the child (due to chronological or developmental age).

- Frequency of night-time awakenings required to give care.
- Administration of enteral feeding (gavages).
- Duration of ventilatory assistance (e.g., more than 14-16 hours/day).
- Dependence on ventilatory assistance (the child cannot tolerate not being ventilated; rapid deterioration if ventilation stops, minimal respiratory reserve).
- Lack of or difficult communication with the child (e.g., child unable to call for help).
- Equipment difficult to adjust (because of the size of the child).
- Soft tissue trauma caused by the interface requiring skin care prior to installation of the interface.
- Frequent changes of position are necessary, even at night.
- Intensity of concurrent respiratory treatments other than ventilatory assistance itself (e.g., physiotherapy, aspirations, cough assist).
- High co-morbidity.

^bSuggested non-medical criteria for increasing the recommended allowance (see right-hand column) (non-exhaustive list):

- 1) Single-parent family OR family at risk of breakdown (as identified by multidisciplinary assessment).
- 2) Siblings under 3 years of age and not attending an early childhood center (or other child care system).
- 3) Physical or mental health problems in the parent or caregiver.
- 4) Siblings with significant physical or mental disability.
- 5) Child protection risks evident.

5. NON-INVASIVE VENTILATORY ASSISTANCE WITH CPAP ^{b, c}			
Type of care	Needs of the child	Average time required to provide respiratory care	Recommended allocation on average for the home (as an indication)
5.1 Basic intensity	<ul style="list-style-type: none"> - The child is usually ventilated at night only. - The child can install the interface or help with its installation. - The child is able to collaborate with the care (NB: in some cases, especially in adolescence, the patient is able to collaborate but refuses to collaborate). - The child can communicate care needs and is able to call for help. <p style="text-align: center;">OR</p> <ul style="list-style-type: none"> - The child cannot help with care and requires assistance with the installation and adjustment of the interface. However, the child is well adapted to the CPAP and tolerates it well and, in most cases, does not require overnight intervention to replace the interface. 	Approximately 30 min per day	—
5.2 High intensity	<ul style="list-style-type: none"> - The child is ventilated at night and may need to be ventilated during the day. - The child requires assistance with the installation and adjustment of the interface; the interface often needs to be replaced several times during the night. - The child is unable to assist with care. - The child may have difficulty communicating or calling for help. - The child often requires aspiration of secretions, especially at night during respiratory infections. 	Approximately 30-60 min/day PLUS: several night-time interventions to replace the interface ^a	50 hours/week (i.e., 5 nights/week at 10 hours/day) for the first two months, then to re-evaluate If the need for night-time interventions persists because of developmental impairment, provide 20 hours/week of support (i.e., 2 nights at 10 hours/day), to be reassessed regularly (e.g., every 6-12 months)

^a This situation is seen at the beginning of treatment in young children under five (5) years of age and in children with developmental disabilities and may compromise the success of CPAP. In children with developmental disabilities, the need for multiple night-time interventions may persist for years.

^b Key elements associated with increased parental work for children with CPAP:

- Respiratory infections (increased secretions, ventilation hours often increased).
- Little or no cooperation from the child (due to chronological or developmental age).
- Frequency of night-time awakenings required to give care.
- Administration of enteral feeding (gavages).
- Lack of or difficult communication with the child (e.g., child unable to call for help).

- Equipment difficult to adjust (because of the size of the child).
- Soft tissue trauma caused by the interface requiring skin care prior to installation of the interface.
- Frequent changes of position are necessary, even at night.
- Intensity of concurrent respiratory treatments other than ventilatory assistance itself (e.g., physiotherapy, aspirations, cough assist).
- High co-morbidity.

^cSuggested non-medical criteria for increasing the recommended allowance (see right-hand column) (non-exhaustive list):

- 1) Single-parent family OR family at risk of breakdown (as identified by multidisciplinary assessment).
- 2) Siblings under 3 years of age and not attending an early childhood center (or other child care system).
- 3) Physical or mental health problems in the parent or caregiver.
- 4) Siblings with significant physical or mental disability.
- 5) Child protection risks evident.

6. INVASIVE VENTILATORY ASSISTANCE BY TRACHEOSTOMY ^{b, c}			
Type of care	Needs of the child	Average time required to provide respiratory care ^a (including direct care and monitoring)	Recommended allocation on average per week for the home (as an indication)
6.1 Moderate intensity	<ul style="list-style-type: none"> - The child is ventilated at night only. - The child can clear secretions independently, so it is rare, apart from during respiratory tract infections, that the child requires aspiration of secretions during the daytime. - The child may assist with care or provide own care. - The child understands the risks associated with the presence of the tracheostomy. The child can call for help if needed. - The child usually tolerates respiratory infections fairly well, with no increase in ventilatory requirements. - The child usually attends school. - The child usually feeds by mouth without the need for gavages (enteral nutrition). <p><i>During periods of ventilatory assistance:</i></p> <ol style="list-style-type: none"> 1) The child must be monitored with a pulse oximeter and respirator alarms; during these periods the child should be under the supervision of a caregiver who can intervene in the event of complications or if an alarm sounds. 2) The child must be supervised by a skilled and trained caregiver who is awake at his bedside and able to intervene in the event of complications (a life-threatening complication can occur at any time). <p><i>Outside periods of ventilatory assistance, the child must be supervised by a trained caregiver who is able to assess the child's respiratory status, including bronchial congestion, and if necessary be able to intervene appropriately.</i></p>	<p>Day care: Approximately 30 min per day</p> <p>PLUS: on waking up, access at all times to a trained caregiver who is able to intervene as required</p> <p>PLUS: at night, presence on site of an awake trained caregiver at the bedside, i.e., 10-12 hours/day 7 days/week)</p>	<p>70 hours/week (i.e., 7 nights/week at 10 hours/day)</p>
6.2 High intensity	<ul style="list-style-type: none"> - The child is ventilated at night and during naps. In many cases, the child also needs ventilatory assistance during the day when awake. - The child often does not tolerate even a brief interruption of ventilatory assistance (a child who is completely dependent on ventilatory assistance does not tolerate any interruption of ventilation). - Respiratory infections make the child fragile and unstable and often increase the need for ventilation up to 24 hours a day. 	<p>Tracheostomy care (see section 3. above) (can be up to 2.5 hours/day or 18 hours/week)</p> <p>PLUS: outside periods of ventilatory assistance, on waking up: direct supervision (eyes -on) at all times by a trained person able to intervene as required</p>	<p>86-100 hours/week (i.e., 2-3 days/week at 8-10 hours/day and 7 nights/week at 10 hours/day)</p>

	<p>In addition, the following characteristics are often observed:</p> <ul style="list-style-type: none"> - The child may have difficulty communicating or calling for help because of age or developmental impairment. - The child requires feeding (enteral nutrition). <p><i>During periods of ventilatory assistance:</i></p> <ol style="list-style-type: none"> 1) The child must be monitored with a pulse oximeter and respirator alarms and during these periods the child should be under the supervision of a caregiver who can intervene in the event of complications or if an alarm sounds. 2) The child must be supervised by a skilled and trained caregiver who is awake at his bedside and able to intervene in the event of complications (a life-threatening complication can occur at any time). <p><i>Outside periods of ventilatory assistance, the child must be supervised, directly “eyes-on” by a trained caregiver who is able to assess the child’s respiratory status, including bronchial congestion, and if necessary be able to intervene appropriately.</i></p> <p>If attending school, the child needs a trained attendant, able to start ventilation on site and intervene in case of deterioration OR attends a specialized school adapted to care needs with skilled personnel able to intervene as needed.</p>	<p>PLUS: during periods of ventilatory assistance: presence on site of an awake skilled trained caregiver, 16-24 hours/day 7 days/week</p>	
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^a **To determine the time required to provide care**, we drew directly from the Canadian Thoracic Society's 2017 recommendations for required surveillance (Amin R, et al. Pediatric home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline executive summary. *Canadian Journal of Respiratory, Critical Care and Sleep Medicine*. 2017;1:7-36).

^b **Invasive ventilatory assistance by tracheostomy at home for children: key elements associated with increased parenting tasks:**

- Duration of ventilatory assistance.
- Little or no cooperation from the child (due to chronological or developmental age).
- Administration of enteral nutrition (gavages).
- Lack of or difficult communication with the child (e.g., child unable to call for help).
- Respiratory infections (increased secretions, ventilation hours often increased).
- Frequent changes of position are necessary, even at night.
- Intensity of concurrent respiratory treatments other than ventilatory assistance itself (e.g., physiotherapy, aspirations, cough assist).
- High co-morbidity.

^c **Suggested non-medical criteria for increasing the recommended allowance (see right-hand column) (non-exhaustive list):**

- 1) Single parent family.

- 2) Siblings under three (3) years of age and not attending an early childhood center (or other child care system).
- 3) Physical or mental health problems in the parent or caregiver.
- 4) Siblings with significant physical or mental disability.
- 5) Child protection considerations at play.
- 6) Family at risk of disruption (as identified by multidisciplinary assessment).

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