APPENDIX A: description of gradual respiratory failure, acute respiratory failure and disease progression and palliative care

Gradual Respiratory Failure
Individuals with progressive respiratory muscle weakness and other restrictive thoracic disorders (ALS; myotonic dystrophy, Duchenne muscular dystrophy) undergo a typical sequence of respiratory compromise, leading from normal unassisted gas exchange, to nocturnal hypventilation with normal daytime gas exchange, and eventually to respiratory failure. Daytime hypercapnia and other symptoms of sleep-disordered breathing develop but can be corrected with the institution of nocturnal non-invasive assisted ventilation (NIV). The simplicity, cost and acceptability of NIV has led to this approach being widely adopted and considered first line therapy in the management of chronic respiratory failure. Importantly, it is now recognized clinically that ventilatory support during sleep is all that is required to achieve sustained daytime improvements for most patients. Even individuals who require additional daytime ventilation can be supported with NIV continuously to correct gas exchange abnormalities avoiding detrimental aspects of tracheostomy placement.

Weakness of the pharyngeal and expiratory muscles of these individuals creates additional problems resulting in diminished cough effectiveness and increased pneumonia risk. Access to and frequent use of non-invasive inspiratory and expiratory respiratory aids (manual cough assist devices) is paramount to pneumonia prevention.

Acute Respiratory Failure
Patients may survive an acute illness that requires mechanical ventilation in an ICU, however are unable to sustain independent ventilation once the acute illness resolves. These ‘chronically critically ill’ patients may remain medically stable but require continued dependence on invasive ventilation via tracheostomy tube. Functional (e.g. neuromuscular and respiratory muscle weakness) and cognitive impairments, both pre-existing and newly acquired, are common. Prognosis at one year is guarded for these patients but some are able to return to community care despite an ongoing need for mechanical ventilation, but the task can be challenging.

In either scenario above, chronic mechanical ventilation (CMV) is required. The application of this technology may be either nocturnal or continuous OR invasive (though a tracheostomy tube) or non-invasive (using face mask or mouthpiece interface). CMV may also be further sub-defined as follows:
- Prolonged Mechanical Ventilation (PMV) = the actual or anticipated need for mechanical ventilation (invasive or non-invasive ≥12 hours per day) in a critical care unit for 21 days or more.
- Long-Term Mechanical Ventilation (LTV) = the actual or anticipated need for any mechanical ventilation (invasive or non-invasive; nocturnal only or continuous) beyond the critical care unit for survival or quality of life.

Disease Progression and Palliative Care
Due to disease progression or development of new problems clinicians, patients and care providers need to remain vigilant to any potential changes in symptoms and either initiate pre-determined care plans or seek further assessment. Multidisciplinary review and management change may be required. Initial and ongoing discussions regarding the patient’s wishes with respect to medical management in case of acute deterioration or end-of-life care issues need to be established. For example, whilst tracheostomy and invasive ventilation offers longer survival, it is associated with significantly greater burden of care and cost to the patient, care providers and / or community. Palliative care services must be accessible before they reach the advanced stages of their disease. Discussion and documentation of advanced directives regarding resuscitation status and treatment end points must be encouraged.

RETURN TO EXECUTIVE SUMMARY
SECTION II. Transition to Home (Patient admitted to hospital)

**Introduction**
Although chronic respiratory failure and the consequent need for long-term ventilatory support can result from a variety of diagnoses, in all cases, there are constants to be addressed when transitioning to home. There are both medical and nonmedical factors that determine the suitability of a VAI to go home on ventilatory support. A comprehensive assessment must be performed by an interdisciplinary health care team to provide the necessary training to make a successful transition to home – ideally with a rehabilitative approach.

**Key evidence**
Prospective observational studies and retrospective reviews based on small numbers of patients comprise the evidence base for the recommendations on the transition to home. The strength of the recommendations informing this section is primarily based on the consensus of the HMV committee. Current publications address different aspects of the factors influencing successful transition of VAIs to home. Randomized control studies in this topic are unlikely to be conducted.

**Conclusion**
The transition to home is a complex and demanding process for VAIs, and require highly sophisticated technology. Effective initiation and optimal monitoring of treatment are essential elements of successful HMV. The HMV committee recommends that an interdisciplinary team of health care professionals is of utmost importance for successful transition to home – provided that decisions are made under the leadership of a physician who is experienced in long-term ventilation. Commitment, motivation and preparation from patients’ families and caregivers are also crucial for a successful transition to HMV. Family preparation is especially important in the establishment of care at home for VAIs who are not fully independent.

Prospective users of HMV need to be advised that acquiring equipment, learning how to use it and preparing the home environment can take a significant amount of time. Furthermore, the needs of the patient, family, caregivers and the home health care team must each be taken into consideration during this initial process. The interface of the VAI and the ventilator (invasive or noninvasive), for example, will greatly influence the complexity of individual care plans.

Many VAIs do not have the level of personal or third-party insurance to cover the initial costs of the ventilator and associated respiratory equipment. In addition, if the equipment malfunctions or fails, they may not have the resources to repair or obtain replacement in a timely fashion, thus increasing the likelihood of a return to hospital. Therefore, it is strongly suggested that a publicly funded system to support VAIs in the community be available and include timely access to equipment, maintenance services and a structured, ongoing educational program. Such a program is also expected to facilitate the transition to home, thus reducing hospital days.

**SECTION II. Recommendations**

1. **The candidate should be medically stable without constant or frequent monitoring, tests or treatment changes.** (Consensus)

2. **The candidate and family must be motivated** (Consensus):
   - • VAIs must express interest in transitioning/living in the community.
   - • The family should express commitment to having the VAI live in the community.
   - • The family is willing to provide support (physical, emotional and financial).

3. **The candidate must have an adequate home setting** (Consensus):
   - • Identifiable home to live in, suitable to the needs of the VAI.
   - • Home is adaptable as necessary.
4. **The candidate must have sufficient caregiver support** (Consensus):
   - Caregivers identified and committed to provide sufficient hours of care to meet the needs of the VAI.
   - Available government-funded care hours identified.

5. **The candidate must have access to adequate financial resources** (Consensus):
   - Sources of financial assistance identified and accessed.
   - Sufficient financial resources available to meet projected costs.

6. **The candidate must have access to equipment appropriate for the needs** (Consensus):
   - Appropriate equipment selected and ordered.
   - Sources for ongoing supplies identified.

7. **There must be comprehensive initial training, plus ongoing education and training for patient and caregivers once they are in the home setting** (Consensus):
   - Initial education organized to accommodate learning, practice and inclusion of caregivers in the care routine as early as possible.

8. **The candidate must have access to health care support in the community** (Consensus):
   - Follow-up care available as appropriate (tracheotomy tube changes, ventilator reassessments and assessment of the ongoing effectiveness of the ventilatory support).
   - Medical follow-up to allow for appropriate changes to the mode of ventilation (i.e., from invasive to noninvasive and vice versa, from continuous to nocturnal and vice versa).
   - Professional services available post discharge.
   - A government-funded ventilatory service is necessary to provide appropriate access to equipment and respiratory care.

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Client Care Model Pictorial Representation

The model is graphically depicted as a triangle, indicating that the volume of clients at the base of the triangle is anticipated to be large and populations at the top of the triangle are smaller. The arrow on the far right hand side illustrates that the populations near the top of the triangle require higher resource and care coordination intensity.

Clients can move up and down the triangle between the different populations as their health conditions change. The Acute Episode bar running along the left side of the triangle illustrates that an acute episode can occur for any of the populations. In addition, the Acute Episode bar is wider near the top of the triangle to indicate the increased frequency of acute episodes with the Complex and Chronic populations near the top of the triangle.
### Client Care Model – Population and Sub-Population Definitions

<table>
<thead>
<tr>
<th>Complex</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Complex</td>
<td>1 or more health/chronic conditions with complicating factors; Direct care needs are unstable &amp; unpredictable; The individual or support network is not self-reliant with high risks in more than 1 area; RAI score 17+; High/intensive coordination is required to support client goals &amp; outcomes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adult</th>
<th>Age range: 19-54 years old; Multiple care partners across sectors; overall poor coping; multiple complex psychosocial issues; unmanageable behavioral/mental health issues;</th>
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<tr>
<th>Senior</th>
<th>Age range: 65+ years old; Multiple care partners across sectors; overall poor coping (significant caregiver distress); multiple complex psychosocial issues; unmanageable behavioral/mental health issues; possible clinical conditions: moderate to late stage dementia</th>
</tr>
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</table>

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<tr>
<th>Palliative</th>
<th>Difficult/unmanageable pain and symptoms; Unpredictable trajectory; management of End-of-Life care/death issues anticipated to be complex; high risk of dying somewhere other than preferred place; Prognosis &lt; 6 mos.; Palliative Performance Scale (PPS) score (suggested guideline): 0-30%</th>
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</thead>
</table>

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<tr>
<th>Chronic</th>
<th>1 or more health/chronic conditions with complicating factors; Direct care needs are stable and predictable; The individual is self-reliant and/or can achieve stability with the right support network; RAI score 11-15; Moderate care coordination intensity is required to support client goals &amp; outcomes</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Adult</th>
<th>Age range 19-54 years old; Requires assistance to continue with age-related roles;</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Senior</th>
<th>Age range: 65+ years old; Age-related morbidities</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Palliative</th>
<th>Pain and symptoms are manageable; predictable trajectory; high likelihood of death in preferred place; Prognosis &gt; 6 mos.; Palliative Performance Scale (PPS) score (suggested guideline): 40-60%</th>
</tr>
</thead>
</table>

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<tr>
<th>Community Independence</th>
<th>May have one or more health/chronic illnesses; Capable of independent living; Has a stable support network and/or can be self-reliant; RAI score 1-10; Low care coordination intensity is required to support client goals &amp; outcomes</th>
</tr>
</thead>
</table>

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<tr>
<th>Supported Independence</th>
<th>Focused &amp; time-limited engagement of services to promote safety &amp; independence (anticipate discharge &lt; 1 year but may be on longer); Proactive linkages to community support services, as applicable to prevent deterioration of function; RAI score 1-6</th>
</tr>
</thead>
</table>

<p>| Stable at Risk | Focused engagement of services to promote safety &amp; independence (uncertain care trajectory); Proactive linkages to community support services, as applicable, to prevent deterioration of function; RAI score 7-10; |</p>
<table>
<thead>
<tr>
<th>Short Stay</th>
<th>Typically require short term education, care or support as a result of illness, injury or disability; High potential to return to independence; stable and predictable care trajectory; Overall very low care coordination intensity with a focus upon exceptions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>High capacity to transition to self-care; Potential CCAC Service needs – Injections, IV, catheters, drain care, simple ostomy, key paths/care paths related to health education;</td>
</tr>
<tr>
<td>Oncology</td>
<td>High capacity to transition to self-care; May require CCAC services 90-180 days (or beyond); Active treatment for cancer with or without metastatic disease</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>High capacity to transition to self-care; Expectation is therapy focus on specific issue(s) with predictable outcomes and timeframes. Use of pathways, as applicable.</td>
</tr>
<tr>
<td>Wound</td>
<td>High capacity to transition to self-care; Focus on intervention is wound care; Typically new admissions; Use of pathways, as applicable.</td>
</tr>
<tr>
<td>Well</td>
<td>Does not have a chronic or acute illness that requires direct services; Person is self-reliant and manages health needs; health needs relate to health promotion and prevention; Interested in future care planning</td>
</tr>
</tbody>
</table>
APPENDIX D – Community Respiratory Therapy – process flow map showing how Community Respiratory Therapy is integrated into the on-going care process

Grey Bruce Health Services – Owen Sound
RETURN TO EXECUTIVE SUMMARY
APPENDIX E - Operational Metrics for the Appropriateness of Care Transitions

Language describing key transition points help to define an integrated system of care for patients requiring Chronic or Prolonged Mechanical Ventilation (PMV). It can also be used to categorize and document the operational metrics needed to ensure that the venue of care and its resources are provided in a timely, safe, effective, patient-centred, and efficient manner.

**Figure 10 Transitions – Present Working Model 2013**

**Source:** Dr. David Leasa, Respirologist LHSC
Model Definitions

- **Transition points** – Patients requiring chronic mechanical ventilation (prolonged or long-term mechanical ventilation) receive care in a variety of settings. Transfer between care settings is common. Definitional criteria of key transition points across the care continuum for these patients are outlined below.

- **PMV** – More than 3600 critically ill patients are admitted to the LHSC intensive care units each year. Delayed weaning (>21 days) and continued dependence on mechanical ventilation called prolonged mechanical ventilation (PMV) occurs in ~5%. The human and financial costs of this dependence are substantial. Although most patients are eventually weaned or die of their illness, some remain dependent on ventilation, which is provided invasively through a tracheostomy or non-invasively by a facemask. In a few Canadian jurisdictions (not London), ‘chronic assisted ventilation areas’ and/or ‘weaning units’ outside of the ICU may coordinate this care.

- **LTMV** – Patients that remain ventilator dependent within an ICU may have the potential for quality of life in other care settings. This requirement for LTMV is on an indefinite basis. They need to be identified and prepared for home or other community ventilation, if appropriate. Other patients living in the community may be ‘at-risk of’ developing ventilator failure. They also need to be identified and prepared for home or other community ventilation. LTMV can be: invasive (via tracheostomy); noninvasive through a facemask or mouthpiece interface; nocturnal only; or continuous in use.

Operational Metrics

Data analysis is vital for strategic planning, quality improvement and demonstration of program impact to health service organizations and the LHIN. The present focus is on defining operational metrics to describe the characteristics of transfers between care settings for the Chronic Mechanical ventilation (CMV) patient.
Data Collection –
For any patient transition (see below) the healthcare provider requesting the transfer will document the following:

- Care setting prior to the transition
- Care setting after the transition
- Date/time stamp the request for transition; actual date of transition
- All criteria should be met for the patient to be considered an ‘appropriate’ transfer (i.e., the transition setting is appropriate to deliver the required service)

Table 8 Criteria to define transitions within the CMV care continuum
(Credit to Dr. David Leasa, Respirologist LHSC)

Transition Criteria

The following are possible criteria that could be further developed to help define operational metrics for the appropriateness of care transitions for CMV patients.

1. Transition from ventilation in the acute phase of illness to PMV

Criteria that should define transition

<table>
<thead>
<tr>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient stability from a physiological perspective</td>
</tr>
<tr>
<td>Repeated unsuccessful weaning attempts</td>
</tr>
<tr>
<td>The patient’s wishes</td>
</tr>
<tr>
<td>The patient’s prognosis</td>
</tr>
<tr>
<td>Quality of life</td>
</tr>
<tr>
<td>Availability of appropriately trained staff and resources to facilitate transition</td>
</tr>
<tr>
<td>The need for nocturnal non-invasive ventilation alone</td>
</tr>
<tr>
<td>An established routine for ventilation and weaning</td>
</tr>
<tr>
<td>The patient’s diagnosis</td>
</tr>
<tr>
<td>Patient motivation and agreement to transition</td>
</tr>
<tr>
<td>Availability of expertise in ventilator weaning</td>
</tr>
<tr>
<td>Patient characteristics</td>
</tr>
<tr>
<td>Family motivation and agreement to transition</td>
</tr>
</tbody>
</table>

2. Transition from PMV to LTMV

Criteria that should define transition

<table>
<thead>
<tr>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient stability from a physiological perspective</td>
</tr>
<tr>
<td>Establishment of a transition plan</td>
</tr>
<tr>
<td>Option of withdrawal of care is discussed</td>
</tr>
<tr>
<td>Acceptance and motivation of the patient based on informed choice</td>
</tr>
<tr>
<td>Redefinition of the goals of care/care plan</td>
</tr>
<tr>
<td>Patient’s prognosis</td>
</tr>
<tr>
<td>Requirement for invasive mechanical ventilation on an indefinite basis</td>
</tr>
<tr>
<td>Patient care needs can be managed in a community or a long-term care facility</td>
</tr>
<tr>
<td>Capability of the healthcare team to manage LTMV</td>
</tr>
<tr>
<td>Acceptance/motivation of family/informal caregivers based on informed choice</td>
</tr>
<tr>
<td>Likelihood of acceptable quality of life</td>
</tr>
</tbody>
</table>
Availability of an appropriate interface (e.g. facemask or tracheostomy)

Patient’s diagnosis

Requirement for non-invasive ventilation on an indefinite basis

Patient’s inability to participate in decisions (i.e. if persistent vegetative state or similar, should not be classified as LTMV)

Availability of appropriate resources

Availability of a transition placement

Family desire to assume care

3. Transition from PMV or LTMV to acute critical care ventilation (reverse transition)

Criteria that should define transition

Acute loss of physiological stability

The patient’s and family’s wishes for full intervention for reversible condition

Need for escalating medical/health care that cannot be provided in current environment

Patient’s wishes

Availability of resources outside of ICU to manage LTMV i.e. patients should not be admitted to an ICU solely because ventilated

Existing plan of care/advanced directives agreed by patient, family and healthcare team

Non-acute/progressive deterioration of medical condition warranting acute critical care

Planned admission for redefining care plan

Withdrawal of life support when resources to do so are not available in the patient’s community

Community placement availability i.e. need to return to an acute care institution due to unavailability of community placement

4. Transition from institutional care to care within the community (home/assisted living)

Criteria that should define transition

Availability of ongoing access to continuing interprofessional care

Willingness and ability of supportive network comprising family/friends/caregivers to provide required care

Adequate modification of environment/physical space to accommodate patient and equipment

Informed choice on behalf of the patient to live in the community

Physiologic stability of patient to live in the community

Availability of appropriate support for informal caregivers including respite

Client/caregivers ability to demonstrate required knowledge/skills to live in community safely

Availability of equipment that is adequately funded and resourced

Availability of a most responsible physician to lead care

Established plan of care for ongoing management

Realistic expectations of family caregivers

Availability of necessary community resources

Ability to secure required resources/supports in a timely manner
Availability of formal caregivers
Physiologic stability for a minimum number of days
Availability of financial support for caregivers, equipment, supplies, medication, and healthcare professionals
An absence in delay in transition once community resources are ready
Stable and uncomplicated airway
Ability of patient to direct care
Patient’s prognosis

Patient’s ability to tolerate brief interruptions in ventilation

5. Transition from ‘at-risk of’ to ‘requiring’ long-term mechanical ventilation

Criteria that should define transition

Recurrent/progressive ventilatory failure without complicating treatable acute illness/reversible factors
Degree of physiologic impairment
Acceptance and motivation of the patient based on informed choice
Symptom profile
Likelihood of acceptable quality of life
Patient’s diagnosis
Medical prognosis
Time i.e. duration of symptoms/ventilatory failure; time from diagnosis
Access to appropriate healthcare personnel and technology
Availability of resources

6. Transition from paediatric to adult LTMV services

Criteria that should define transition

Transfer of care from paediatric team/specialists to adult team/specialists
A plan that commenced in adolescence that views transition as a continuum
Chronologic age
A transition plan being in place
Appropriate environment/equipment for developmental stage
Appropriate environment for physical size
Availability of trained/skilled healthcare workers
The likelihood of an acceptable quality of life
Adequate resources in the adult sector
Family readiness
Patient readiness
Persistent vegetative state i.e. withdrawal of care should be discussed with parents/guardians of these children as opposed to considering transition to adult services
Patient’s underlying condition
7. Transition from active treatment to end of life care for PMV or LTMV

Criteria that should define transition

- Patient exhibiting prolonged suffering (physical, mental, emotional, spiritual)
- Patient’s advance directives or expressed wishes based on informed choice
- Informed consent from the patient or appropriate designate
- The goal for palliation/comfort care
- Family/surrogate decision maker wishes based on informed choice
- Best anticipated functional outcome no longer being acceptable to the patient
- Quality of life
- Patient, family and healthcare team agreement on plan for end of life care
- Patient values (cultural/religious/moral)
- Current accepted professional and ethical standards
- Illness that is irreversible and/or non-treatable
- Ability to medically manage end of life process in resource appropriate manner
- Physiologic endpoints
- An appropriate environment
- Multisystem organ failure
- Availability of team with specialized palliative care support
- Healthcare team agreement

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APPENDIX F – Reference Documents

The following documents were used to help inform the development of this discussion paper.


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Respiratory Care, January 2002 Vol. 47 No1 Evidence-Based Guidelines for Weaning and Discontinuing Ventilatory Support A Collective Task Force Facilitated by the American College of Chest Physicians, the American Association for Respiratory Care, and the American College of Critical Care Medicine

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