

A Commitment to Excellence and Partnerships

A Systems Model to meet the health and supportive care needs of Adults living with Chronic Mechanical Ventilation in the South West LHIN

November 4, 2013

Final - as endorsed by the project Steering Committee

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Executive Summary

Links to the main body of this report have been inserted into this Executive Summary – see highlights

Introduction

The purpose of this paper is to outline the health and supportive care needs of [adults living with chronic mechanical ventilation](#); to identify service gaps and how to address them, and, to outline a systems approach to addressing the needs of this population on an on-going basis.

Adults living with chronic mechanical ventilation (or CMV) are a [diverse group](#) both in terms of the reasons why they are living with this chronic condition and the complexity of their needs. Some are able to live at home with family support; others require 24x7 professional supports provided by nurses and/or others. Some can live for many years with this condition, while others do not. Some acquire the need for CMV as adults and others have this dependency from an early age in childhood. With this diversity there is no one solution and individual needs and circumstances need to be at the forefront of any decision-making. The population of [adults living with CMV is expected to grow](#) and as such steps need to be taken now, by putting the necessary the structures and processes in place, to be able to address future needs as they emerge and as they are identified.

A system of care and support

The needs of people living with CMV include health and community support care services, hospital and community services, temporary and permanent care settings, mobile in-home visitation services and complex and intensive care services. The services specifically addressed in this paper include: hospital-based services – both acute and complex continuing care, in-home support services, respite care, adult day programs, specialized assisted living housing, LTC homes, community respiratory care, physiotherapy, primary health care and the role of academic health sciences centre/network. The services provided are governed and managed by a variety of organizations that work under different mandates and legislation and funding mechanisms. In sum, there is significant diversity among the services that share responsibility for this population - at the same time there is a need for all of these organizations and services to work together to deliver high quality services to these individuals and their families. They also need to be able to address current and future needs, as a system of services.

On the basis of a shared commitment all participating organizations and care providers need to work together for the benefit of adults living with chronic mechanical ventilation; continually improving the quality and cost-effectiveness of services; sharing accountability for on-going collaboration; and, committing to formalizing, supporting and sustaining the proposed 'system'.

Guiding Principle #1 – [A patient/client and family centred system of care and support](#)

- All participating organizations and providers are committed to collaborating and working in partnership [with patients/clients and families to identify and meet the health and supportive care needs of the person living with CMV in a way that respects their values, priorities and choices.](#)

Guiding Principle #2 – [System Coordination and Leadership](#)

- All participating organizations and independent providers are committed to work together to provide an integrated system of health and supportive care that serves this population in a timely and seamless manner, and are jointly accountable for the quality, effectiveness and operational efficiency of the system.

Recommendation

It is proposed that all participating organizations, funded by the South West LHIN, establish a collective accountability framework to establish and sustain the regional system of care and support, and that a Regional Oversight Committee with a regional role¹ be established with the following mandate:

- *To ensure that the system of care and support for adults living with CMV is truly patient and family-centred*
- *To improve quality and outcomes for clients/patients*
- *To sustain the system in terms of building regional care capacity to accommodate the increasing number of adults living with chronic mechanical ventilation*
- *To monitor, evaluate and improve [system performance](#)*

¹ Regional refers to all persons served by organizations and services located within the South West LHIN. This includes persons living inside and outside of the South West LHIN boundaries.

- *To support and enable service coordination, development and application of best practices and delivery of high quality care and outcomes*
- *To keep the South West LHIN, participating organizations and independent providers informed of system performance, improvements and challenges*

Guiding Principle #3 – [Service Coordination](#)

- *The system of services is responsive, adaptable and innovative in its response to the permanent and temporary changing needs of individuals whether due to changes in their condition, living situation or other changes that might alter the range or type of services required.*
- *All permanent and temporary transitions of a person, in location, level of care provided, etc. are thoughtfully planned and executed in a coordinated manner to ensure a seamless transition.*

Recommendation

As a mechanism to support the delivery of quality health care and support services to individuals and their families, it is proposed that each participating partner organization designate an existing staff member with the responsibility to be the person to serve as the primary liaison with other organizations for the purpose of coordinating the care of adults living with CMV, especially with respect to planning and implementing transitions in care. These roles would be accountable to the Regional Oversight Committee.

Guiding Principle #4 - [Standards of Care and Support](#)

- *All services, providers, and associated organizations serving this population collaborate and are collectively organized and coordinated to ensure that the same quality and standards of care are provided regardless of the setting or service being provided.*

The ability to deliver on the promise of quality care and support is grounded in the ability to develop, apply and evolve the use of standards of care and support. Some of these standards already exist or have been researched; others may need to be created. Regardless, having standardized tools that can be adapted to the needs of particular environments; being able to educate people in their use; and, being able to reinforce their value is key to providing consistent quality of care and service.

Recommendation

It is proposed that the academic centres in the region (London Health Science Centre and St. Joseph's) assume leadership for the following roles:

- *Providing clinical direction and expertise to others who serve this population*
- *Delivering both clinical training and education to caregivers and other service providers*
- *Serving as an academic centre for both education and research*
- *Playing a leadership role in the development and use of clinical standards and protocols*

Guiding Principle #5 – [Movement and Transitions](#)

- *All permanent and temporary transitions of a person, in location, level of care provided, etc. are thoughtfully planned and executed in a coordinated manner to ensure a seamless transition.*

Current Gaps:

- *There is a lack of pre-planning and defined protocols to guide transitions – both planned and emergency*
- *There are significant gaps and differences as people move from [pediatric to adult services](#) making this a very difficult transition for families – not only for this population but for related groups with complex medical needs with and without technological dependencies.*
- *There is a lack of consistency in introducing [palliative care services](#) to adults with CMV on a proactive basis.*
- *There is a lack of resources and support to fully support planned end of life care with adults with CMV*
- *There are two transitions that require special attention: the transition from pediatric to adult services and the transition to palliative and end of life care. There are significant gaps in service in both of these areas.*

Recommendations:

- *There is a need to develop protocols to pre-plan and manage all transitions.*
- *There is a need for designated roles and resources to manage the transition from pediatric to adult services.*
- *There is a need to strengthen the approach to palliative and end of life care so plans are developed in advance and the resources are in place to implement the plans as defined.*

- *Each organization that has primary responsibility for meeting the needs of an adult living with CMV needs to identify and define a primary contact to facilitate and collaboratively plan and implement all transitions in care – temporary, emergency and permanent.*
- *Leverage the mandate of the CCAC to coordinate access of individuals needing complex care, specialized assisted living, supportive housing, respite care and adult day programs - all of which involve transitions in the setting in which care and support is provided.*

Guiding Principle #6 - [Living at Home](#)

- *People are supported to live at home whenever this is a suitable setting, assuming family members and primary caregivers can provide the support needed through training, education and participation support groups.*
- *Community support services are available to provide additional in-home health and support care, day care and respite care services to people living at home. They provide support needed to enable their primary caregivers to sustain the challenging role of supporting a person living with chronic mechanical ventilation.*
- *[Families are partners](#) in the care of individuals with chronic mechanical ventilation.*
- *Family education and knowledge is seen as essential to a successful partnership in care delivery.*

Current Gaps:

The on-going level of care needed by persons living with CMV at home is difficult to sustain given current funding levels, lack of client and family support and lack of community programs.

There is often a lack of suitable non-hospital options for people living with CMV.

There are challenges in being able to connect with [primary health care services](#).

Recommendations:

- *Increase the availability of [in-home support services](#), in-home and out-of-home [respite care](#), [adult day programs](#), family education and support services to support and sustain families who are able to be primary caregivers.*
- *Provide supports for primary care physicians to support their role in providing on-going primary health care to this population.*

Guiding Principle #7 – [Living in the community](#)

- *[Complex continuing care](#) is provided when and for as long as a person is at too high risk to be cared for in a community setting. Hospital-based complex continuing care is used to provide care for medically complex patients whose condition does not require acute care hospital interventions yet requires regular medical monitoring and onsite physician care and assessment and active care management by specialized staff. Both residential and transitional care is provided by complex continuing care services.*
- *Acute hospital care is used for the delivery of temporary care and treatment to stabilize the person so they can move to another setting for on-going living and provision of day-to-day health and supportive care. Permanent living in acute care is neither patient centered nor fiscally sound.*
- *Community venues and professional services are available to provide specialized home-like living environments to support people in the community when living at home is not an option.*

Current Gaps:

- *At times there are delays in transferring patients into complex continuing care from acute care due to lack of resources, gaps in staff training and skills.*
- *At times there are delays in being able to transfer patients out of complex care due to lack of community options and supports*
- *At times there are delays in being able to transfer a patient out of acute care*
- *At times there are gaps in the services available to support people in the community*

Recommendations:

- *Ensure that any CCC unit in the South West LHIN that serves this population has a collaborative relationship with a Level 3 ICU to support acute care interventions*
- *Provide on-going training and support to CCC staff to serve this population*
- *Provide the necessary funding to support the delivery of CCC services to this population*

- *Develop non-hospital community setting options for people living with CMV when they cannot live at home, ensuring that the options made available address the needs of the individual and at the same time respects their personal values and priorities.*
- *Provide the necessary funding to support the delivery of community options to this population including the funding of designated [LTC homes](#) and [specialized assisted living housing](#)*
- *Provide on-going training and support to staff to serve this population*
- *Through the CCAC fund the delivery of [community respiratory](#) and [community physiotherapy](#) services to serve all people living with CMV in all non-hospital settings*
- *Develop protocols with all Level 3 ICUs to support people living with CMV in their community/catchment area on an as needed basis. This should be extended to include local EMS services responsible for transporting clients/residents/family members to hospital.*

Guiding Principle #8 – [Acute Care](#)

- **Dedicated services and resources are available for the identification and provision of specialized ventilator care needed for the transition of persons requiring chronic ventilation out of institutional (e.g., hospital, ICU) settings.**
- **Specialized care, including scheduled outpatient access to ongoing inter-professional care, is coordinated to support and maintain these individuals in the community.**

Current Gaps:

- *Persons requiring chronic ventilation remain at risk of a long-term stay in an inappropriate setting. Arranging discharges (from ICU or hospital) for ventilator-assisted individuals can be challenging.*
- *Focused specialized care and resources are neither coordinated nor predictable for the timely transfer of these individuals to a more appropriate institutional or community based setting.*

Recommendations

- *Develop a [transitional respiratory care unit](#), outside the ICU, at LHSC, to centralize acute hospital care for post Level 3 ICU in-hospital care of persons requiring chronic ventilation.*
- *Support the development of an LHSC-based inter-professional chronic mechanical ventilation team (nurse, respiratory therapist, physician, etc.) that extends their expertise from the hospital-based transitional respiratory care unit to community, including the use of an outpatient chronic mechanical ventilation clinic.*
- *Support the role of [all Level 3 ICUs](#) to provide ICU-based acute care to adults living with CMV within their catchment area; and support the proactive planning of transfers to acute care, including EMS services.*

Guiding Principle #9 – [Use of Technology](#)

- **Advances in technology that provide a better quality of life or more effective treatment are predictably and proactively applied.**

Current Gaps:

- *Access to mechanical ventilation equipment through the Ontario Ventilator Equipment Pool excludes individuals who live in certain settings – Long-Term Care facilities for example.*
- *[Insufflator/exsufflators](#) that provide cough assistance are not easily accessible when needed.*
- *Installation of equipment to support respiratory ventilation can be delayed due to wait lists for Assistive Devices Program (ADP) approved assessment clinics.*
- *Supply and incidental costs associated with respiratory equipment may be cost prohibitive for some people.*

Recommendations

- *Make mechanical ventilation equipment through the Ontario Ventilator Equipment Pool available to all individuals who require on-going equipment support regardless of where they live.*
- *Make insufflator/exsufflators available through the Ontario Ventilator Equipment Pool or other means.*
- *Ensure that cost of equipment or related items is not a prohibitive factor in terms of a person continuing to live and be supported in the community.*
- *Continue to explore and test the efficacy of new respiratory care equipment through the London Health Sciences Centre's outpatient respiratory clinic.*

1. Introduction

This systems model has been created to define an integrated and coordinated set of services that, by working together, will be able to address the health and supportive care needs of adults who are living with chronic mechanical ventilation.

The model, as outlined in this report is not an implementation plan. It does not specify how many of what kind of services are needed or how much it might cost. That will come later after an implementation plan has been completed.

As a model this report will describe the services that are needed to serve the various needs of this population and how these services need to be organized and work together, as a system.

A fundamental tenant of a system is not only that the parts are defined and roles and relationships are understood but it's also that there is a shared purpose and common vision among the participants. As a multi-organization and integrated system, there needs to be shared governance and accountability for the overall functioning of all the services involved, not just those provided by each participating organization or service provider.

Systems Approach to the Needs of Adults Living with Chronic Mechanical Ventilation

The fundamental goal is to develop an integrated and coordinated approach to meeting the health and supportive care needs of adults living with chronic mechanical ventilation incorporating the full range of clinical and living support needs of this population of adults living within the South West LHIN.

From a population health perspective, the objectives include having an integrated and coordinated system that is capable of:

- Adapting to the needs of each individual and responding quickly to changing needs
- Optimizing the long-term mental and physical health of these individuals
- Optimizing their ability to live as normal and meaningful a life as possible and,
- Minimizing the long-term public cost to providing excellent health and support care to adults living with chronic mechanical ventilation

The Systems Model incorporates the major government funded services needed to fully support adults living with chronic mechanical ventilation. It involves two complementary categories of care services.

The first category is the provision of health care services provided by regulated health professionals or by staff under the direct supervision of a regulated health professional. This category addresses the mental and physical health of adults living with chronic mechanical ventilation, and is divided into two sub-categories: respiratory health and use of mechanical ventilation, and other health issues. These services are based on a medical model of care.

The second category is the provision of supportive care services that support the day-to-day living needs and enhance the well-being of adults living with chronic mechanical ventilation. These services include supporting these individuals with the day-to-day tasks, opportunities and challenges everyone faces each day and include home care, day care, assisted living and supportive housing as well as primary care services that are provided or supervised by a regulated health professional. These services are based on a supportive model of care.

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2. Background

The focus of this project is adults who are living with respiratory failure regardless of cause, that require chronic mechanical ventilation and who need on-going support and care to enjoy the best quality of life available.

Vision

The vision that is driving this project is that we will be able to create a coordinated and integrated system of health and supportive care services that:

- Provides safe, high quality standards-based health care to adults who require chronic (i.e. on-going) mechanical ventilation
- Provides high quality and individualized supportive care that allows these adults to live in the most appropriate, least restrictive setting possible with the day-to-day care support that provides each person with a meaningful life
- Supports these individuals and their families and loved ones through life and living transitions as seamlessly as possible, while providing integrated and coordinated across the spectrum of health and supportive care services they require
- Is responsive, adaptable and able to reflect changing needs, and to apply and develop, teach and adopt best practices

The objectives of the project are:

- To identify the continuum of health and supportive care needed by the range of adults dependent on chronic mechanical ventilation in terms of:
 - the continuum of living settings best suited to address and support their different and changing needs
 - the health and supportive care services needed to support people living in different settings – on site, visiting, on call etc.
 - the health and supportive care specialties required to provide the level of care needed in different settings
 - the full range of resources (human, equipment, facilities, funding, etc.) needed to support the continuum of care as defined
- To identify the structure and organization of services needed to manage and coordinate the delivery of care throughout the continuum including:
 - Trouble shooting and crisis management
 - Managing transitions
 - Planning for and anticipating future system demands, needs
 - Adapting to changes in technologies, public policy, etc. that are likely to impact the care of adults dependent on mechanical ventilation
 - Developing, introducing and adopting changes to the standards of care throughout the continuum on an on-going basis
- To develop specific proposals and advocate for changes that will support the comprehensive and integrated system of health and supportive care that is developed and endorsed by the participating organizations, patients/clients/residents and their families and loved ones
- To ensure that the best interests of the people served are met by a defined system of services, infrastructure, coordination and governance which are implemented and operated effectively, efficiently and responsibly by all participating organizations and health care providers

Deliverables

In terms of deliverables, the project has been divided into three phases

Phase 1 deliverables

- A clearly defined and agreed upon vision
- A model of the continuum of health and supportive care
- A model of the operational processes needed to support system-wide quality of services, transitions, continuity and coordination of health and supportive care

Phase 2 deliverables

- A resource needs analysis and plan to implement the continuum of care and operational model as defined, including the infrastructure, resources and funding need to address gaps and operate the system.

Phase 3 deliverables

- Implementation, on-going operations and sustainability including the structure, processes and resources to support on-going evaluation, process improvements and planning for the future

This report is focused on the Phase 1 deliverables.

This project is sponsored by the following organizations:

London Health Sciences Centre
Participation House Support Services
St. Joseph's Health Care London
South West Community Care Access Centre

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3. Adults living with Chronic Mechanical Ventilation

Definitions:

Mechanical ventilation is a method to mechanically assist or replace spontaneous breathing. This involves a machine called a ventilator. There are two main types of mechanical ventilation: invasive ventilation and non-invasive ventilation.

Chronic Mechanical Ventilation (CMV) includes the following types of patients:

Prolonged Mechanical Ventilation (PMV) - The actual or anticipated need for mechanical ventilation (invasive or noninvasive; ≥ 12 hours per day) in a critical care unit for 21 days or longer.

Long-Term Mechanical Ventilation (LTMV) - The actual or anticipated need for any mechanical ventilation (invasive or noninvasive; nocturnal only or continuous) beyond the critical care unit for survival or quality of life.

Throughout this paper the term Chronic Mechanical Ventilation or CMV will be used along with CMV-IV to indicate invasive ventilation and CMV-NIV to indicate non-invasive ventilation².

There are four primary ways in which people enter the adult system of services.

- **Children with slowly progressive neuromuscular genetic disorders** who, as part of their condition require mechanical ventilation on an on-going basis – may require invasive (IV) or non-invasive ventilation (NIV). They “graduate” into the adult system of services as a function of aging and no longer being eligible for children’s services.
- **Adults with conditions causing diaphragm weakness, chest wall restriction, or abnormal breathing control that result in chronic respiratory failure of a variable, slow, or non-progressive nature such as myotonic dystrophy or kyphoscoliosis** who, as part of their condition require mechanical ventilation on an on-going basis – may require invasive or non-invasive ventilation.
- **Adults who acquire a rapidly progressive neuromuscular disease such as ALS** who, as part of their condition require mechanical ventilation on an on-going basis – may require invasive or non-invasive ventilation.

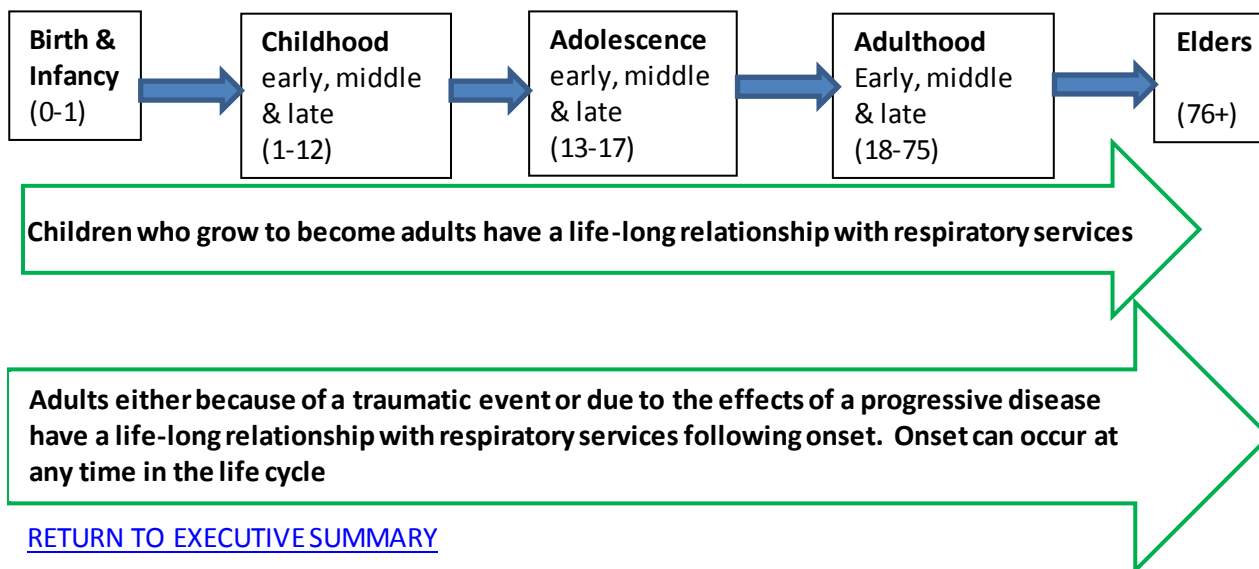
² Delivery of air from a ventilator may be either through a mask firmly held to the face, or through a tube inserted into the trachea toward the bottom of the throat. A mask interface is called noninvasive ventilation, while a tracheostomy tube is called invasive ventilation. Read more: <http://www.surgeryencyclopedia.com/La-Pa/Mechanical-Ventilation.html#ixzz2cbpYycD2>

- **Adults who experience an acute illness or traumatic event** who, as a bi-product of the event have a compromised respiratory system and therefore require mechanical ventilation on an on-going basis – may require invasive or non-invasive ventilation. The untoward event may include a stroke or an accident or other event.

The people who require chronic mechanical ventilation:

- Cover the entire age spectrum
- Have a wide range of diagnoses and causes that have led them to require chronic mechanical ventilation
- The health of most of the people who require chronic mechanical ventilation is compromised in other ways as well – physical disabilities, developmental delays, communications issues. In other words while chronic mechanical ventilation is a life supporting service and necessary for their survival – or quality of life – to continue, it is usually not the only health related issue with which these people are living.

Figure 1: Life cycle stages



4. Data and Demographics

Information Sources

Since there is no central database available from which to profile adults living with chronic mechanical ventilation, the information profiled below reflects the combined profile of patients being served by the Chronic Ventilation Database at University Hospital plus the Sleep and Apnea Assessment Unit at Victoria Hospital. Steps have been taken to request information from Ontario’s Ventilator Equipment Pool (VEP). The Institute for Clinical Evaluative Sciences (ICES @ Western) has agreed to undertake a project, using the OHIP database to profile this population, not only within the South West LHIN but province-wide. This information is not yet available.

Primary Reason for Ventilation

The following table provides a profile of the primary reasons for ventilation by the type of ventilation being used. The table demonstrates that there are a wide range of reasons behind people needing to use mechanical ventilation. Eighty-two percent of the 317 clients in the database required non-invasive ventilation while 18% required invasive ventilation. In both groups of clients, people with ALS were the largest group – 28% overall; although they accounted for 31% of the NIV group and 18% of the IV group of clients.

Table 1

Primary Reason for Ventilation by Type of Ventilation (Non-invasive and Invasive), All clients – active and inactive, August 2013

Primary reason for ventilation	NIV Clients		IV Clients		All Clients	
	#	% NIV	#	% IV	#	%
ALS	80	31%	10	18%	90	28%
Myotonic Dystrophy	24	9%	5	9%	29	9%
Congenital Myopathy	9	3%	4	7%	13	4%
Obesity Hypoventilation Syndrome	54	21%	0	0%	54	17%
Chest Wall Deformity	10	4%	4	7%	14	4%
Primary Diaphragm Paralysis	16	6%	2	4%	18	6%
Central Respiratory Depression	3	1%	7	12%	10	3%
Spinal Cord Injury	4	2%	8	14%	12	4%
Spinal Muscular Atrophy	3	1%	0	0%	3	1%
Complicated Obstructive Sleep Apnea	11	4%	0	0%	11	3%
Chronic Obstructive Pulmonary Disease	7	3%	6	11%	13	4%
Duchenne's Muscular Dystrophy	14	5%	4	7%	18	6%
Fascio-Scapular Humeral Dystrophy	2	1%	0	0%	2	1%
Myasthenia Gravis	3	1%	1	2%	4	1%
Limb Girdle Muscular Dystrophy	5	2%	1	2%	6	2%
Multiple Sclerosis	0	0%	2	4%	2	1%
Guillain Barre Syndrome	0	0%	1	2%	1	<1%
Post-Polio Syndrome	5	2%	0	0%	5	2%
Neuropathy	10	4%	2	4%	12	4%
TOTAL	260	100%	57	100%	317	100%

Data Source: Chronic Ventilation Database (UH); Sleep and Apnea Assessment Unit (VH)

Active Clients

Presently there are 203 active clients (186 or 92% use NIV; 17 or 8% use IV). Current living settings and age profile are displayed below.

Current living settings

The vast majority of people living with **non-invasive ventilation** are able to be at home.

Excluding people who were in acute care, there were 17 active clients who were adults presently living with **Invasive Ventilation** in the LHSC database. Of this total as of August 2013:

- 6 were living at St. Joseph's Parkwood Hospital
- 3 were living in Participation House Support Services
- 1 was living in supportive housing
- 7 were living at home

If we assume that all NIV patients are living at home then overall 95% are living at home.

Table 2
Current Age Profile of Active NIV and IV clients

Age Range	Number of NIV clients	Number of IV clients	TOTAL	%
<20	3	1	4	2%
20-29	17	5	22	11%
30-39	9	3	12	6%
40-49	29	1	30	15%
50-59	35	4	39	19%
60-69	56	2	58	29%
70-79	21	1	22	11%
80-89	14	0	14	7%
90-100	2	0	2	1%
TOTAL	186	17	203	100%

Data Source: Chronic Ventilation Database (UH); Sleep and Apnea Assessment Unit (VH)

This profile of adults living with chronic mechanical ventilation shows that the overall population includes adults of all ages although most are middle-aged to older adults.

Children living with chronic mechanical ventilation

This table does not include children who are living with chronic mechanical ventilation. Information received from the Children’s Hospital at LHSC showed that as of November 2012 there were 19 children living with chronic mechanical ventilation. Of this 19, seven were using invasive ventilation and 12 were using non-invasive ventilation. Three (all invasive) used mechanical ventilation 24 hours a day and the others (16) used it only at night (nocturnal). The ages of the children ranged from 2 to 17 with one or two children in each year.

Table 3
Gender of NIV and IV clients (active and inactive)

Gender	NIV clients	IV clients	Total	%
Female	108	26	134	42%
Male	152	31	183	58%
TOTAL	260	57	317	100%

Data Source: Chronic Ventilation Database (UH); Sleep and Apnea Assessment Unit (VH)

This profile of adults living with chronic mechanical ventilation shows that for the overall population and within each group (NIV and IV) males outnumber females. In the IV group males only slightly outnumber females while in the NIV group almost 60% of the population is male.

Projections of future patient volumes

Projections of future patient volumes were estimated from available sources of historical patient activity. The calculations included consideration of the following:

1. Current Volume

Current volume was based on the patients included in the LHSC respirology database in lieu of timely access to provincial Ventilation Equipment Pool (VEP) database. The database includes information about year of entry into the care of LHSC team, diagnosis, type of ventilation need (e.g. invasive or non-invasive) and years under care prior to death, among other data elements. However, because the database has been active for only two years, the case volumes were too small to segregate projections based on diagnosis. Consequently, projections were segregated on the basis of invasive and non-invasive status only.

2. **New cases**

The annual addition of new cases was based on LHSC respirology database and an overall increase in population of 1% (based on Ontario Ministry of Finance’s population growth projections). All new cases, regardless of whether they died later in the year, were included in yearly recruitment totals for invasive and non-invasive ventilation care.

3. **Rate of decompensation**

The rate at which patient’s needs changed from non-invasive to invasive ventilation was estimated from the LHSC respirology database. Since very few of the non-invasive patients in the database transitioned to invasive care within the two years in which the database has been operational, this consideration was managed by including these patients in the “future new cases” to invasive care.

4. **Death rate**

The death of a ventilator dependent patient was inferred from the LHSC respirology database on the basis of the date that their record was deactivated in the database. Mortality rates were estimated based on the deaths observed in the database as well as the literature and clinical experience of the LHSC respirology program staff.

Assumptions

Population projections were based on the following general assumptions.

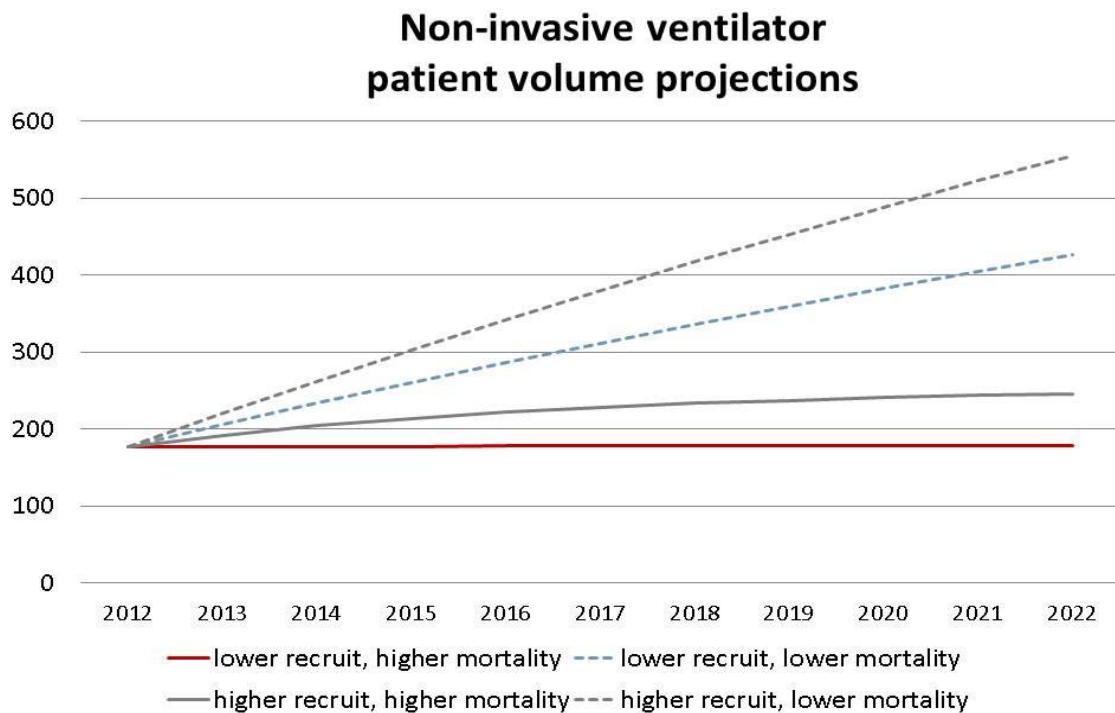
- No changes are made to how care is delivered to this patient population. This may not be a valid assumption as the explicit intent of this discussion paper is to change the current model of care. However, for the purposes of projections, it was not possible or reasonable to estimate the impact of unknown changes on patient volumes and survival.
- All current pediatric patients would age into the adult system and be included in the projections as ‘new cases’ to invasive or non-invasive care
- Patients do not move in or out of the South West LHIN
- For reasons of feasibility and access to data, no adjustment was made based on the expectation that historical increases in smoking will increase volumes of COPD patients (Chronic Ventilation Strategy Task Force 2006). However, this assumption can be confirmed or corrected based on observations in coming years of changes in volumes of COPD patients coming into care, generating changes in projections in proportion to the changing volumes.

Table 4 Population Projection Calculations

data element	Non-invasive	Invasive	Comments
Current volume (2013)	177	16	Based on UH volumes (invasive) and UH and VH volumes (non-invasive)
Annual new cases	33.5	2.5	Based on 2010-2012 UH data (non-invasive) and 2002-2012 UH data (invasive)
Increased annual new cases	48	0	Based on clinical judgement and knowledge of program operations
Annual death rate/100 persons	20	18.75	Non-invasive death rate was based on expected life span of 5 years (i.e. 20%/year for 5 years)
Reduced annual death rate/100 persons	4	3.75	Arbitrarily reduced death rate –for calculation of “contingency” projections to estimate impact of error in death rate estimates
Annual population growth	1%	1%	Based on Ontario Ministry of Finance estimates

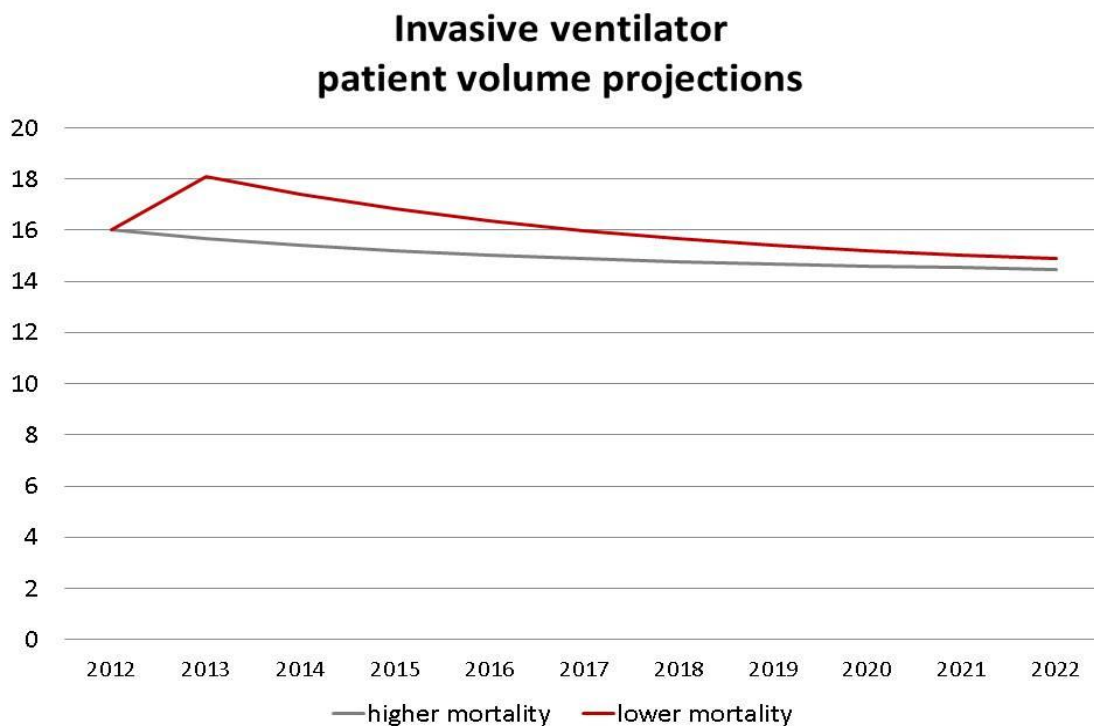
These two charts profile the estimated growth in the number of adults with non-invasive and invasive chronic mechanical ventilation over the next 10 years – to 2022

Figure 2 Non-Invasive ventilator patient volume projections



Source: Projections based on LHSC respirology database circa Feb 2013

Figure 3 Invasive patient volume projections



Source: Projections based on LHSC respirology database circa Feb 2013

This data is presented to provide some sense of the cumulative impact on health care system resources. However, as the gap between the projections based on differing assumptions about new recruitment and death rates show, it is difficult to predict with certainty the precise volumes over a long term. In addition, there are a wide variety of reasons

that cause people to become dependent on mechanical ventilation and affect their survival rates once they become dependent. This is particularly true for non-invasive ventilation; the patterns for invasive patient volumes appear to be more stable.

The reliability of these projections might be increased through the following actions:

- 1) Accessing the provincial VEP database to confirm what proportion of all South West LHIN patients are represented in the LHSC respirology database
- 2) Confirming recruitment and mortality rates by tracking same in the ongoing LHSC respirology database and correcting projections according to the emerging evidence

With the reality of variation in projections in mind, system implementation planning will focus on the next five years – to F2018-19.

Reference Information

Excerpts from the Toronto Central LHIN report, *Long-term Ventilation (LTV) Plan for the Care and Management of Individuals with LTV Needs*, October 2011

Flexibility in capacity planning

Health service providers pointed out that, due to the nature of this population and its changing needs, utilization of capacity can vary over time. There seems to be a certain ebb and flow, resulting in material swings in the demand for inpatient care that are particularly noticeable for small-scale services. Any proposed solutions for inpatient capacity need to recognize the potential variations in utilization, and ensure that capacity is available when needed.

Identification of at-risk individuals

In the adult population, it is difficult to identify individuals at risk of long-term ventilation. Sources of information on these individuals might include, for example, patient advocacy groups, family physicians and respirologists. However, there is a risk that they will prefer not to maintain ties with the LTV community of care providers when they are in a relatively stable period. Without a registry of at-risk individuals, it will be extremely difficult to identify these individuals and conduct system level planning for LTV services.

Meeting the Needs of a Heterogeneous Population

The LTV population is not a homogenous group. Individual circumstances vary according to the nature of the underlying condition:

- Some patients have chronic and degenerative conditions, which result in periods of relative stability, interspersed with periods of acute care needs. In contrast, individuals with an acquired spinal cord injury are typically more stable, with different needs for care. This second group has greater potential for weaning, whereas advanced stage ALS, for example, provides little expectation of weaning.
- These individuals all have a common need for mechanical ventilation. However, the ventilation needs are not always the most difficult aspect of care to manage. Due to the degenerative nature of some of the underlying conditions, many of these individuals also have physical disabilities that increase their care needs.
- The needs of those ventilator-assisted individuals suffering from a degenerative disease are not stable. As the disease progresses, their needs increase. Consequently, frequent monitoring and the flexibility to adjust supporting services to their changing needs are required.
- Some patients can direct their own care; others (e.g., patients with dementia, ALS patients that can no longer communicate or severe brain injury) cannot. The options for care settings are reduced for this latter population.

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5. Defining the services and setting that serve adults living with chronic mechanical ventilation

As noted through the description and profile of people living with chronic mechanical ventilation, they reflect a wide range of people living with different conditions and with varying needs. What they all have in common from the perspective of this project is that they are all dependent on a mechanical device for breathing and breathing support. In many other ways they are different.

The setting and services described below are not exhaustive. Rather, the focus is on the health and supportive care services needed by adults who are dependent on chronic mechanical ventilation. It is acknowledged that particular individuals may well use other services due to unrelated conditions or diseases that are not included in this model.

As noted in Section 2.0 Background the vision is to create an integrated system of health and supportive care services that seamlessly meets the current and changing needs of adults dependent on chronic mechanical ventilation.

In general terms this vision can be translated into the following set of guiding principles related to the health and supportive care provided to adults dependent on chronic mechanical ventilation.

- All participating organizations and providers are committed to collaborating and working in partnership with patients/clients and families to identify and meet the health and supportive care needs of the person living with CMV in a way that respects their values, priorities and choices.
- All participating organizations and independent providers work together to provide an integrated system of health and supportive care that serves this population in a timely and seamless manner, and is jointly accountable for the quality, effectiveness and operational efficiency of the system.
- The system of services is responsive, adaptable and innovative in its response to the permanent and temporary changing needs of individuals whether due to changes in their condition, living situation or other changes that might alter the range or type of services required.
- All permanent and temporary transitions of a person, in location, level of care provided, etc. are thoughtfully planned and executed in a coordinated manner to ensure a seamless transition.
- All services, providers, and associated organizations serving this population collaborate and are collectively organized and coordinated to ensure that the same quality and standards of care are provided regardless of the setting or service being provided.
- All permanent and temporary transitions of a person, in location, level of care provided, etc. are thoughtfully planned and executed in a coordinated manner to ensure a seamless transition.
- People are supported to live at home whenever this is a suitable setting, assuming family members and primary caregivers can provide the support needed through training, education and participation support groups.
- Community support services are available to provide additional in-home health and support care, day care and respite care services to people living at home. They provide support needed to enable their primary caregivers to sustain the challenging role of supporting a person living with chronic mechanical ventilation.
- Families are partners in the care of individuals with chronic mechanical ventilation.
- Family education and knowledge is seen as essential to a successful partnership in care delivery.
- Complex continuing care is provided when and for as long as a person is at too high risk to be cared for in a community setting. Hospital-based complex continuing care is used to provide care for medically complex patients whose condition requires a hospital stay, regular onsite physician care and assessment and active care management by specialized staff. Both residential and transitional care is provided by complex continuing care services.

- Acute hospital care is used for the delivery of temporary care and treatment to stabilize the person so they can move to another setting for on-going living and provision of day-to-day health and supportive care. Permanent living in acute care is neither patient centered nor fiscally sound.
- Community venues and professional services are available to provide specialized home-like living environments to support people in the community when living at home is not an option.
- Dedicated services and resources are available for the identification and provision of specialized ventilator care needed for the transition of persons requiring chronic ventilation out of institutional (e.g., hospital, ICU) settings.
- Specialized care, including scheduled outpatient access to ongoing inter-professional care, is coordinated to support and maintain these individuals in the community.
- Advances in technology that provide a better quality of life or more effective treatment are predictably and proactively applied.

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5.1. Patient/Client and Family Engagement

System Overview

Patient/client engagement involves the comprehensive and ongoing relationship that each adult living with chronic mechanical ventilation has with the participants in the system.

The first dimension is the provision of patient/client centred care as fundamental to every care/service interaction between the patient/client and each care provider, which is recognized as the foundation of providing a positive and respectful experience, whether in an acute, chronic or supportive care environment.

The second dimension is the active involvement of the patient/client in the coordination and planning of their care. The tailoring of services to meet a patient/client's specific needs and preferences needs to be "based on shared responsibility between patients/clients and caregivers"³. As Dr. Sara Singer from the Harvard School of Public Health has pointed out in a recent presentation, integration frequently describes attempts to achieve better coordination of services but where patient care is the object of integration, its definition must account for the role of the patient – in other words integrated patient care = coordinated + patient-centered care. The traditional patient: provider relationship needs to be framed or defined as a partnership and collaboration where the provider has certain areas of expertise and knowledge and the patient/client and their families have others; namely, critical insights into the life of their family member as well as their own needs and capabilities, how their life and that of their loved one has been lived and how they want it to continue. This is a principle tenant of the [Chronic Care Model](#) that while originally developed in the USA, has been adopted by the World Health Organization and applied throughout the world including Ontario.⁴

The third dimension is to extend this partnership to the engagement of patients/clients in aspects of system management such as assessing the quality of care received, evaluating the system's performance, and forecasting future care needs.

Sharing Information - the Circle of Care

In the health care field the people who make up the constellation of providers who share responsibility for providing care to a specific person are referred to as the "circle of care". Being part of a circle of care means that confidential information can be shared among the members. **When family members are involved, especially as primary caregivers, they need to be part of this Circle of Care.**

³ This language is taken from a webinar sponsored by the Conference Board of Canada at which Dr. Sara Singer Harvard School of Public Health, Harvard Medical School, and the Mongan Institute for Health Policy/ Mass General spoke of her work to measure the patient experience of care integration – April 18, 2013. <http://www.conferenceboard.ca/e-library/abstract.aspx?did=5419>

⁴ Chronic Care Model – [Ontario version](#)

The functions of a Circle of Care, while protecting the wishes and privacy of the patient/client, and confidentiality of information are as follows:

- To coordinate the planning and delivery of care services needed by each patient/client;
- To ensure quality of care through the use of evidence-based care practices and standardized protocols;
- To accommodate the individualized needs and wishes of each patient/client.

A wide variety of people could be included in an inclusive circle of care. While it is true that the types of information and protection of confidentiality needs vary across the various providers who may provide health or support care to an adult living with chronic mechanical ventilation, the fundamental principle is that care providers need the information relevant to performing their duties in a safe, appropriate and efficient manner. Hence there is likely to be private and confidential information that is not shared among all members of a patient/client's care team. Information needs and the nature of the involvement in specific care planning activities will depend on the nature of the care roles of each Circle of Care member.

Proposed Future State - Patient/client and family engagement

The relationship between patients/clients and the participating services, caring for adults living with chronic mechanical ventilation needs to be defined by a shared responsibility model – a partnership – that is tailored to each patient/client's needs and preferences and those of their family.

Once the coordinated and integrated system is established, patients/clients and families need to be engaged in providing feedback and input on the quality of care received and in identifying opportunities for system improvements.

Service providers and adults with chronic mechanical ventilation and their families need to jointly identify best practices in providing collaborative patient centred or patient directed care and develop a way to ensure that this approach to their care is applied and promoted as much as possible.

Recommendation 5.1.1

It is recommended that families and adults living with CMV be active members of the proposed system oversight committee and that the Terms of Reference be designed to reflect their participation.

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5.2. Hospital-based Services

5.2.1. Acute care

System Overview

In acute care hospitals that have intensive care units, there are different levels that define the level of care they are able to provide. Level 3 ICU services are the highest level and Level 2 ICU beds are the next highest⁵. Most but not all hospitals that have Level 3 ICU services also have Level 2 services but many smaller hospitals only have Level 2 ICUs. There are other types of critical care beds such as trauma and cardiac critical care beds but ICUs specialize in ventilator intervention and support.

⁵ Definition of Level 3 Critical Care Units - All Level 3 units are capable of invasive ventilator support.

Capable of providing the highest level of service to meet the needs of patients who require advanced or prolonged respiratory support, or basic respiratory support together with the support of more than one organ system. This is generally considered a "full service" Critical Care unit despite the fact some specialized services may not be available (e.g. dialysis).

Definition of Level 2 Critical Care Units

Capable of providing service to meet the needs of patients who require more detailed observation or intervention including support for a single failed organ system, short-term non-invasive ventilation, post-operative care, patients "stepping down" from higher levels of care or "step ups" from lower levels of care. These units provide a level of care that falls between the general ward (Level 1) and a "full service" Critical care unit (Level 3). Level 2 units **do not** provide invasive ventilator support.

Source: South West LHIN Moderate Critical Care Surge Protocol

http://www.southwestlhin.on.ca/uploadedFiles/Public_Community/Current_Initiatives/Critical_Care/South%20West%20LHIN%20Moderate%20Surge%20Action%20Plan%20FULL%20PACKAGE.pdf

One of the requirements of Level 3 ICUs is that invasive mechanical ventilation can be offered on a short-term basis. For Level 2 ICUs this involves non-invasive ventilation. In both cases the expectation is that a person needs mechanical ventilation on a short-term basis following which they can be transitioned to another service or setting without needing mechanical ventilation. Hurdles arise when this does not occur and prolonged mechanical ventilation (NIV or IV) is required.

When a person is admitted to hospital in respiratory distress and is medically unstable, the Level 3 ICU is usually the appropriate setting for them to receive the level of care they need. A distinguishing feature of a Level 3 ICU is the ability to provide on-going ventilator support. A Level 2 ICU is expected to provide only temporary ventilator support (up to 24 hours).

The following description outlines the acute care treatment and leadership role of a Level 3 ICU that serves people with respiratory distress on a temporary basis. Some of these services may be provided in a Level 2 ICU setting within the same hospital when a person is less critical.

Level 3 Intensive Care Unit – inpatient acute care role

- To intervene at the onset of respiratory distress when a person's life is at risk
- To stabilize the person's ability to breathe using therapeutic interventions and respiratory equipment
- To initiate and support both non-invasive and invasive mechanical ventilation
- To remove or "wean" a person from mechanical ventilation when they no longer need it
- To participate in the planning and transition of people from the ICU
- To provide follow-up and back-up support, if required, for persons discharged from the ICU

According to the literature, if a patient requires mechanical ventilation for more than 21 days, for at least six hours a day, it is considered prolonged⁶. Having a patient remain in a Level 3 ICU for an extended period of time makes the ICU less available to other critically ill patients but the lack of options can force this situation to occur. One of the first and most important strategies deployed is to try and wean a person safely from their dependency on mechanical ventilation. This is most important as it significantly improves the quality of life of the individual. The alternative strategy is to move them – when they are more medically stable - to a less intensive setting – within the same environment (to a Level 2 ICU for example). Where the volume of patients is warranted, this might involve a dedicated transitional respiratory care unit. This might be typical of a large regional tertiary care centre.

Many models of transitional care have been pursued, given the pressure on ICU facilities and the effect on patient flow through blocking of an ICU bed by long stay patients. Venues of care are varied, depending upon jurisdiction, and include acute care hospitals (both ICU and step-down units), ventilator-dependent rehabilitation units (VDRU), specialized long-term acute care hospitals (LTACH), and respiratory high-dependency care units (RHDCU). Specialist weaning centres, geographically distant from general ICUs, have also been developed to manage patients with PMV. The nurse-patient and respiratory therapist-patient ratios are less than continuing care in the ICU, allowing reduced costs. However, patient transition among these venues may also be punctuated with episodes of acute critical illness and need to return to ICU.

The following is a quote from the literature (Italy) describing one type of transitional respiratory care unit.

*Respiratory High-Dependency Care Units for the burden of acute respiratory failure.
European Journal of Internal Medicine 23 (2012) 302-308.
Author: Raffaele Scala.*

Respiratory High-Dependency Care Units (RHDCUs) for the clinical governance of acute respiratory failure

The term RHDCU refers to specialized units for patients that provide an intermediate level of care between the ICU and the ordinary ward where non-invasive monitoring and assisted ventilation techniques are mainly, even if not exclusively, applied. The RHDCU acts as "step-down unit" for stabilized patients transferred from ICU (i.e. weaning and decannulation) and as "step up" unit for cases not responding to medical therapy in Emergency Departments or wards. They work as a critical link that integrates the timing and level of care of respiratory patients between the ICU, Emergency Department and general hospital wards. The availability of an

⁶ Prolonged Mechanical Ventilation (PMV) is defined by the Centers for Medicare and Medicaid Services in the United States as greater than 21 days of mechanical ventilation for at least six hours per day. <http://www.uptodate.com/contents/management-and-prognosis-of-patients-requiring-prolonged-mechanical-ventilation>

“intermediate-respiratory” setting to manage “mono-organ” decompensations avoids the dangerous “under-assistance” in low-care general ward environment and the futile “over assistance” in a high-care ICU environment.

RHDCUs provide a specialist quality of care for the clinical management of ARF (acute respiratory failure) that optimizes the use of health resources. In fact, compared to the direct and indirect high costs spent by traditional ICUs, RHDCs reduce both types of costs by their lower nursing staff requirements, by ensuring that admissions to ICU are confined to those patients who require intensive treatment, and by allowing early discharge from ICU for those patients that now only require weaning from the ventilator.

Besides lower costs there are other advantages which favour the RHDCU over ICU. More privacy for the patient and easier visitor access may contribute to the “healing” process and earlier discharge, especially for those patients requiring long-term oxygen-therapy/and or home mechanical ventilation. Last but not least, is the high level of expertise that a multi-professional team of doctors, nurses and physiotherapists working in an RHDCU can develop when they are led by a dedicated pulmonologist, which manifests itself in three important areas:

- 1) Non-invasive ventilation (NIV), which is usually applied by means of masks (nasal or facial) or helmet with dedicated positive pressure ventilators or, for a few centres, by means of negative-extra-thoracic pressure ventilators (i.e. iron lung);
- 2) Protocol-driven procedures to facilitate the weaning of invasively ventilated patients from ventilation support;
- 3) Discharge planning of ventilator dependent chronically ill patients (such as those affected by neuromuscular diseases) which require a high level of assistance, training of caregiver’s, links with extra-hospital facilities, telemedicine etc.

Such a unit would have both expertise and allocated resources to do the following:

- Wean medically stable patients from mechanical ventilation, if possible
- Transition a person from one type of ventilator to another when the change will improve their quality of their life and where the transition may put the person at risk and require immediate intervention
- Educate patients, family members, caregivers and others involved in the person’s life about how to use the ventilator, what to look out for, issues, risks, how to intervene etc.
- Provide a high level of clinical and medical expertise in the acute treatment of persons with chronic mechanical ventilation needs regardless of where they live
- Work collaboratively with other organizations and with the patient/client and family to determine the most appropriate transition, when transition to another setting is deemed appropriate
- Re-admit CMV patients from the community during periods of decompensation or loss of medical stability

Transitional Respiratory Care Unit

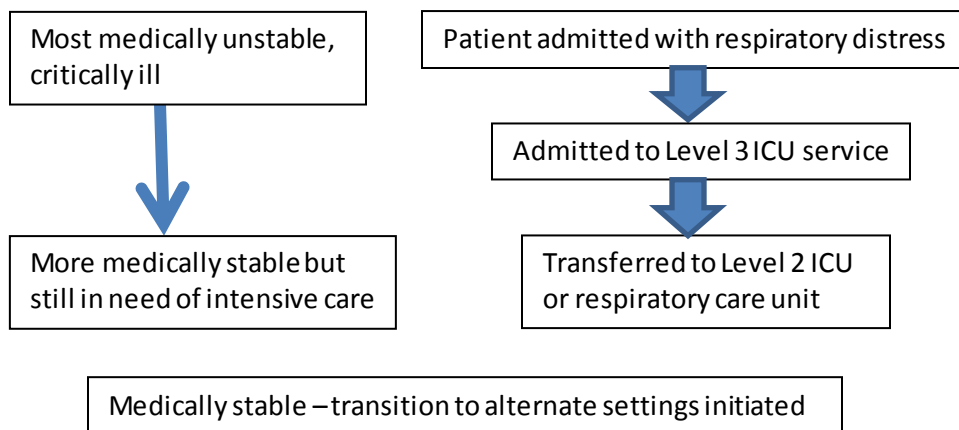
Weaning from the temporary use of mechanical ventilation is part of the respiratory service provided in the ICU. When prolonged mechanical ventilation is involved it means that the person’s respiratory system is compromised on an extended or permanent basis. Treating and supporting a person with this dependency requires highly specialized physician and staff interventions. When weaning from mechanical ventilation cannot be done then prolonged non-invasive ventilation – either 24 hour or nocturnal or invasive ventilation needs to be considered.

The transitional respiratory care unit is positioned as an adjunct to the formal Level 3 ICU service to support patients with mechanical ventilation that still need acute care but not Level 3. This way they receive care within the acute care setting but with a new focus – positioning and readying them for transition to another care setting. If the prevalence of prolonged mechanical ventilation does not support a dedicated unit then using a Level 2 ICU for this purpose provides a cost-effective alternative and allows planning for transfer to a more appropriate, longer-term setting to take place⁷.

The process outlined below can apply to persons who are newly diagnosed or to those CMV patients who are admitted due to their becoming unstable while living in another setting. For those whose health is most fragile and vulnerable ready access to Level 3 ICU services is critical – especially if they are dependent on invasive mechanical ventilation.

⁷ Excerpt from *Long-term Mechanical Service Inventory Program Final Summary Report*, July 31, 2008, MOHLTC, Priorities for Care and Services (p. iv) **Create intermediate care beds.** The creation of intermediate care beds in an acute setting (ideally close to the ICU to facilitate access to services if needed and to support staff) is a preferred alternative to keeping these patients in the ICU. Many LHINs suggested the development of “flexible” beds to fill short-term needs for ventilator-assisted individuals. These beds could serve multiple purposes such as weaning, high acuity care, home ventilation training, reassessment and respite care.

Figure 4 Patient Flow – Acute Care



A key message is that the hospitals that treat this population need to have the clinical expertise to meet these needs. While there is considerable variability in the scope and complexity of the acute care needs of adults living with chronic mechanical ventilation they are all vulnerable from a respiratory perspective. It is a chronic condition and they have an on-going need for mechanical ventilation (varying from: invasive; noninvasive; nocturnal and intermittent; to 24 hour support). At the same time many have other medical complexities that go beyond their respiratory needs. The expectation, however, is that once a person is medically stable from an acute care perspective a decision can be made to transition to an alternate, less intensive environment.

Implications for the South West LHIN

Current State – acute care

Inpatient Services

At the present time there are three hospitals in the South West LHIN that provide both Level 3 ICU and post Level 3 ICU care to patients who are dependent on mechanical ventilation for a prolonged period of time – Grey Bruce Health Services (GBHS) – Owen Sound site and London Health Sciences Centre (LHSC) – both University and Victoria Hospitals.

GBHS has both a Level 3 and Level 2 ICU service and transfers patients from Level 3 to Level 2 as they become more stable. The number of patients they encounter who become dependent on mechanical ventilation is relatively low and therefore this model fits with their needs and circumstances. GBHS – Owen Sound is the only hospital site in the counties of Grey and Bruce that has Level 3 ICU beds; all other hospital sites with ICU beds in this area have Level 2 ICU services. There is therefore a natural referral pattern into Owen Sound when patients in this area need Level 3 ICU services. Even if a patient presents at another hospital in the area, once they are assessed and stabilized for transport they are transferred to Owen Sound. As part of managing the demand for ICU services they not only transition people from their Level 3 to their Level 2 unit but GBHS has trained the staff at its Warton hospital site, a primary care hospital, to care for medically stable CMV-IV patients. This is a creative option born out of the need to manage scarce resources, leverage existing capacity and the current lack of community options.

In the central part of the LHIN (Huron and Perth counties) the small primary care hospitals do not have ICU beds and a number of others have Level 2 services. Huron Perth Healthcare Alliance's Stratford General Hospital site is the only hospital in this area that has Level 3 and Level 2 ICU services. Given their geographic proximity to London they tend to transfer patients who require prolonged mechanical ventilation to LHSC.

In the southern part of the LHIN, there are a number of hospitals with Level 3 ICU services (LHSC, St. Thomas Elgin General Hospital, Woodstock General Hospital and Tillsonburg District Memorial Hospital). LHSC has by far the largest number of adult Level 3 beds – 68 in total between University and Victoria Hospital. Some of these are special purpose and not general ICU beds⁸. It is at University Hospital that a specialization in adults with chronic mechanical ventilation has been developed, fostered and supported. The Children's Hospital on the Victoria Hospital

⁸ There are 30 medical-surgical-trauma beds at Victoria Hospital (CCTC). At University Hospital there are 24 medical-surgical ICU beds (MSICU) and a 14-bed cardiac surgery recovery unit (CSRU).

site has many areas of pediatric specialization and one of these is working with children who are dependent on mechanical ventilation. The Children's Hospital serves children from throughout Southwestern Ontario and beyond.

LHSC Critical Care has a vested interest in ensuring that patients are identified early and managed appropriately to avoid inappropriate or long-term use of ICU resources that could otherwise be utilized to meet the needs of other critically ill patients. At University Hospital the Extended Intensive Care Unit (EICU or Bay 6 - 5 beds) is designated within the Medical Surgical Intensive Care Unit (MSICU) to meet the ongoing care needs of patients with uncertain hospital discharge disposition, low acuity of illness, physiologic stability and anticipated or actual need for prolonged mechanical ventilation (PMV). The goals of care include: reducing monitoring intensity; optimizing cognition and communication; pain and symptom management; establishing routines of advancing mobility and independence through rehabilitation; improving nutritional state; and weaning from mechanical ventilation (if possible). Communication with patients and families about prognosis, achievable goals of treatment, and alternatives to the continuation of critical care is essential. Within this cohort are patients that remain ventilator dependent (either invasive or noninvasive) with potential for quality of life outside of an ICU. Identification and preparation of such patients appropriate for home or other community ventilation becomes an important focus. There is no adjacent Level 2 ICU service or an intermediate or transitional respiratory care unit to which to transfer. This creates access issues for patients needing Level 3 ICU care.

At Victoria Hospital patients requiring prolonged mechanical ventilation (PMV) are managed within the Critical Care Trauma Centre (CCTC). Protocols exist to facilitate ventilator discontinuation, similar to the EICU, although patients requiring PMV are not grouped physically within the CCTC. Support exists outside the CCTC for patients requiring chronic non-invasive ventilation through the respirology service and the Sleep and Apnea Assessment Unit. Transition support and training for community care, along with outpatient follow-up, for those needing chronic invasive mechanical ventilation would come from the EICU clinicians.

In addition to the role of GBHS and LHSC, all hospitals with Level 3 ICUs need to prepare to become involved with the CMV population. For example, there are instances in which a person, in order to live at home, or closer to home will live near or in a community with a hospital with a Level 3 ICU that is neither Owen Sound nor London. In these circumstances it is important that the local Level 3 ICU staff is prepared to support the transition of the patient into their community or catchment area, be part of the decision-making process and be prepared to respond on an as needed basis.

Chronic Mechanical Ventilation Outpatient Services

In addition to inpatient care, both GBHS – Owen Sound and LHSC provide non-emergency outpatient respiratory services for CMV patients, primarily through clinics. This is an important way to provide on-going care, monitor functioning and re-direct the course of clinical intervention. The role of outpatient respiratory services for people living with CMV is summarized below:

- To monitor and assess a person's respiratory state and functioning on an on-going basis
- To recommend changes or modifications in practices to reduce risks and improve the quality of life
- To transition a person from one type of equipment to another when the transition does not require hospitalization
- To educate patients, family members, caregivers, staff of community support services and others involved in the person's life about how to use the respiratory equipment, what to look out for, issues, risks, how to intervene etc.
- To support both non-invasive and invasive mechanical ventilation
- To safely initiate non-invasive ventilation, in the 'at-risk' individual, when hospitalization is not required
- To consult other clinicians (complex continuing care, community hospital and community support services) on respiratory and related health care concerns that typically arise with adults living with chronic mechanical ventilation
- To support a care plan that aligns with the patient's goals of care (e.g. end of life, etc.)
- To refer patients to the Sleep and Apnea Assessment Unit (Victoria Hospital), as needed, when further studies are needed to better define ventilator prescriptions.

The outpatient clinic plays an on-going and pivotal role in the lives of people living with chronic mechanical ventilation. It not only serves as a transitional resource to help prepare a person to move from hospital to the community but it also serves as the on-going service that provides specialized respiratory support and interventions that help prevent re-hospitalization. For example, if a person is going through a change in respiratory equipment it is this clinic that can implement that change and educate service providers and caregivers in its proper use. They will also prescribe how often equipment is to be used if it is to be used intermittently. Their knowledge and expertise can play a key role in assessing the effectiveness of a prescribed piece of equipment and its use; flagging concerns; and, making changes as needed. The staff of this clinic can also work closely with CCAC, community provider teams,

and complex continuing care. In many ways the outpatient service plays a key role to ensure people are able to live in the community and that the respiratory care they are receiving is as effective as possible.

GBHS and LHSC both provide outpatient clinics. The LHSC clinic is a specialized one for CMV patients. The GBHS clinic operates a general respiratory outpatient clinic and CMV patients are part of this general clinic run by their respirologist. As noted earlier this is most appropriate given the relatively low volume of CMV patients being served. It is noteworthy that the GBHS respirologist, in addition to having a clinic in Owen Sound, also runs a respirology clinic in Kincardine two times a month.

At LHSC there are a number of other specialized clinics that serve this population for condition specific issues; for example there is the Neuromuscular Disease Clinic (UH), the Multidisciplinary Motor Neuron Diseases Clinic (UH), and the Sleep and Apnea Assessment Unit (VH). The primary clinic that serves the population for respiratory muscle weakness is the outpatient chronic ventilation care clinic at University Hospital.

Proposed Future State – acute care

For important geographic and access to care reasons, it is important that GBHS – Owen Sound continue to maintain the capacity to serve adults with chronic mechanical ventilation needs as they are at present – through both inpatient and outpatient services. This includes having the specialized medical, nursing and allied health resources – especially the medical, respiratory and physiotherapy services to serve this population of patients. GBHS should continue to serve as a hub for the northern part of the LHIN and surrounding area.

Given the level of expertise that has been developed by LHSC and the geographic proximity of LHSC to communities and hospitals in the southern and central part of the LHIN, it is proposed that the University Hospital site of LHSC play a leadership role, in collaboration with the other Level 3 ICUs in the area, in addressing the acute care needs of adults with chronic mechanical ventilation, especially those living in the central and southern parts of the LHIN.

From an inpatient acute care perspective all Level 3 ICUs should be prepared to address the needs of CMV patients that live within their catchment area.

Recommendation 5.2.1.1

It is recommended that both LHSC and GBHS continue to provide both inpatient and outpatient services for the CMV population and both sites should expect and plan for growth in the volume of patients being served over time. The opportunity to provide both outreach and virtual clinics should be assessed on an on-going basis.

Recommendation 5.2.1.2

It is recommended that LHSC develop a proposal to create a Transitional Respiratory Care Unit to serve this population.

Recommendation 5.2.1.3

It is recommended that LHSC provide clinical consultation to the Level 3 ICUs (as needed) in the southern and central part of the LHIN regarding CMV patients, especially when a respirologist is not on site to provide medical leadership.

Rural hospitals may be able to accommodate adults living with chronic mechanical ventilation for acute care issues in order to provide care closer to home when other options are not available, however a formal linkage with a Level 3 ICU is essential.

Recommendation 5.2.1.4

It is recommended that any rural community hospital in the South West LHIN that serves adults living with chronic mechanical ventilation be required to establish a formal working partnership with a Level 3 ICU.

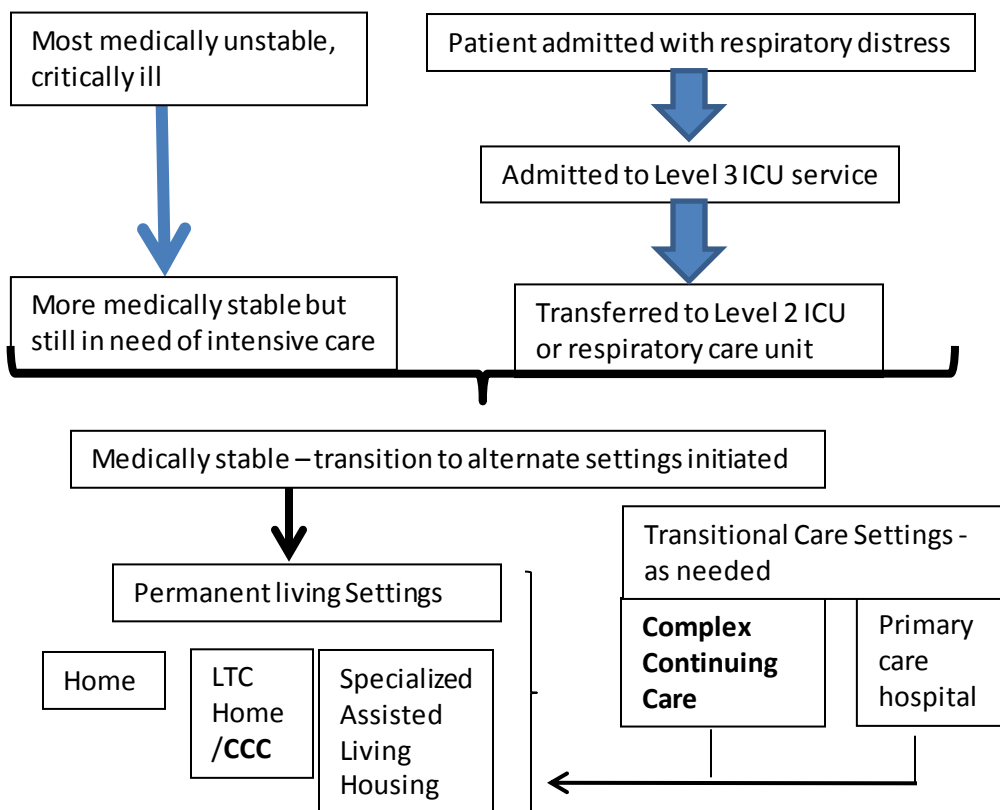
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5.2.2. Complex Continuing Care

System Overview

Complex Continuing Care (CCC) provides both transitional and residential care to support individual needs and is needed when a person's chronic or complex condition requires continuing medical management, skilled nursing and a range of interdisciplinary, diagnostic, therapeutic or technological services and these needs cannot be met through primary health care, community services or Long-Term Care Homes. Complex Care provides both transitional and residential care to support individual needs and will transition individuals to a community setting (e.g. home or other residential living) when possible.

Figure 5 – Patient Flow from acute to complex continuing care



In many communities, complex continuing care is provided by the same hospital that provides acute care. In larger urban areas this may not be the case.

When CCC units admit a patient living with chronic mechanical ventilation they are most often people who are using non-invasive mechanical ventilation. Only in circumstances where special training, staffing and funding is in place would a CCC unit serve people who are using invasive ventilation.

The following description outlines the role of a CCC unit that serves people using both non-invasive and invasive ventilation.

Complex Continuing Care - inpatient role

- To provide on-going care and therapeutic intervention to a medically stable person with chronic mechanical ventilation needs – as well as other needs the person may have – until or if they are able to transition to a community setting – this varies from person to person
- To participate in the planning and execution of transitions of people from acute care to complex care
- To support invasive and non-invasive mechanical ventilation in the medically stable person
- To provide a high level of clinical expertise in the treatment and care of persons with chronic mechanical ventilation needs in a complex continuing care environment
- To address the primary health care needs of the person if chronic care is the primary living setting for an individual rather than a temporary or transitional setting

- To focus on providing on-going care and support for persons unable to live elsewhere and increasing stability to enable a transition to life in the community
- To work closely with other organizations to facilitate and support the person's transition out of complex care
- To work collaboratively with other organizations and with the patient/client and family to determine the most appropriate transition, when transition to another setting is deemed appropriate
- To provide follow-up and back-up support for persons discharged from complex care

In terms of transitioning people from acute care into a non-acute care setting, CCC is one of the options to be considered along with a transition to home or alternate community setting. Depending on the options available, a primary care hospital might be most suitable, especially in rural areas where options can be limited.

Given the needs of this population and the fragile nature of their condition it is essential that there is a close working relationship between CCC services or primary care hospital services and the nearest acute care Level 3 service so that acute care support is available at all times and that there is an established protocol for activating a transfer to the acute care Level 3 ICU as needed, assuming this is part of the care plan that is in place.

Implications for the South West LHIN

Current state – complex continuing care

At the present time there are no hospital-based complex continuing care services in either Grey or Bruce counties in the South West LHIN although on June 26, 2013 the South West LHIN approved the establishment of 10 CCC beds for this area. Having these beds in place might provide an alternative setting to acute care as GBHS currently uses its Wiarton hospital site to accommodate adults with chronic mechanical ventilation (IV) needs when Level 2 ICU care is no longer needed. Adults with CMV have also been placed in other community hospitals in this area.

In the central part of the LHIN (Huron and Perth counties) there are currently 76 CCC beds located as follows: Stratford (20), St. Marys (5), Seaforth (10) [HPHA total is 35]; Listowel (25), Wingham (12) [LWHA total is 37]; Exeter (South Huron Hospital) (4). All of these CCC beds are part of a larger hospital that also has acute care beds. Although the South West LHIN has not made a decision about the future of these beds, a report has been tabled with the LHIN that calls for the number of CCC beds in this area to be reduced from 76 to 73 – see table below. Information has not been collected to determine if there are patients using mechanical ventilation in any of these beds. If there are, it can be expected that they would be using non-invasive ventilation.

In the southern part of the LHIN there are currently a number of hospitals that offer CCC services and they currently offer a total of 190 beds - Woodstock (33), Alexandra Hospital, Ingersoll (14), Tillsonburg (16), St. Thomas Elgin General Hospital (45), Parkwood hospital – London (82). In London CCC is provided at St. Joseph's Parkwood Hospital, a stand-alone CCC and rehabilitation hospital. All hospitals other than Parkwood Hospital also provide acute care services.

Table 5 CCC Beds by Region – Current & Future Recommendations

Regional	Current	2013	2016	2021
North (Grey & Bruce)	0	10	20	41
Central (Huron & Perth)	76	73	74	84
South East (Norfolk & Oxford)	63	38	39	44
South West (Middlesex & Elgin)	45	30	31	35
London (City of London)	82	85	87	98

Excerpt from the South West LHIN Complex Continuing Care & Rehabilitation Final Report Executive Summary March 29th 2012

On June 26, 2013 the South West LHIN approved a recommendation to decrease the number of CCC beds at St. Thomas Elgin General Hospital by 15 beds (from 45 to 30), to decrease the number of CCC beds at TDMH by six (from 16 to 10) and to decrease the number of CCC beds at Alexandra Hospital, Ingersoll by nine (from 14 to 5).

Currently, in the South West LHIN the only CCC setting with a resourced unit dedicated to serving people who use Invasive Ventilation (or IV) is St. Joseph's Parkwood Hospital. They presently have six beds to serve this population. They work in close partnership with the Level 3 ICU respiratory team at LHSC and transfer patients to this service when acute care intervention is required. Parkwood Hospital also supports a number of NIV patients elsewhere within their CCC services.

Proposed Future state – complex continuing care

Adults living with chronic mechanical ventilation should be considered suitable candidates for CCC placement by the Community Care Access Centre provided acute care Level 3 ICU support is available.

In general, complex continuing care services provide both a transitional and residential need for the medically complex individual. Patients admitted to CCC have a combination of complex/medically fragile interacting and chronic medical conditions, which does not require acute care hospital interventions yet requires regular medical monitoring regular on-site physician care and active care management by a skilled interdisciplinary team. When patients no longer need the level of care and services within a CCC, they should be transitioned home or to an alternate community setting. Being able to address the CCC needs of adults living with CMV requires specialized skills and resources. Physicians and staff benefit from working with this population on an on-going basis. Skills, knowledge and insights improve over time and therefore so does the quality of care.

For the purpose of providing CCC-based care, given the relatively small number of persons living with CMV it is proposed that within each geographic sub-area of the LHIN (north, central and south) specific CCC units be identified as designated or preferred settings. Using the language of the South West LHINs IHSP these settings would be considered multi-community in scope. For the London-Middlesex area, Parkwood Hospital will continue to be the designated CCC service.

In terms of selection criteria for the central and north, especially for people using invasive ventilation, one criterion could be the availability of a Level 3 ICU in the same facility. This criterion currently applies to HPHA – Stratford, St. Thomas Elgin General Hospital, Woodstock General Hospital and Tillsonburg District Memorial Hospital.

For care involving people using non-invasive ventilation who need CCC-based care, in addition to having a formal Level 3 ICU relationship, the setting should be located as close to the patient's family and loved ones as possible, assuming that they play an active role in the person's life. Given the expected increase in this population, CCC services can expect to need to plan to serve additional persons, even if this is on an incremental basis over time.

Recommendation 5.2.2.1

It is recommended that within the South West LHIN, CCC services for adults living with chronic mechanical ventilation, for the purpose of offering CCC-based care and serving people who are using invasive ventilation, be considered multi-community in geographic scope; that at least one designated setting be located within each of the sub-LHIN areas (north, central and south); and, that preference be given to CCC units located within hospitals with a Level 3 ICU.

Parkwood Hospital has both the experience and expertise to serve this population from a CCC perspective. Where capacity building is needed in other CCC settings, Parkwood Hospital should be available to provide an outreach and consultation service.

Although it is predicted that the number of adults living with CMV will grow is hard to predict when specific individuals will need specific services. Decisions will need to be based on the needs of the patient and their placement in the most appropriate setting. The ability to move people into alternate living situations will play a key role in determining bed availability but access should always be possible and needs to be planned for on a long-term basis.

With the growth in the population of people living with chronic mechanical ventilation a portion will need CCC services. Since CCACs will be managing the wait list and referral process they are ideally positioned to be able to document, monitor and access the need for CCC services by adults living with chronic mechanical ventilation.

Recommendation 5.2.2.2

It is recommended that the South West CCAC take the lead in monitoring the use and need for CCC beds by the CMV population and from a systems perspective use this information to support the mandate of the proposed system oversight committee to assess the service needs of this population throughout the South West LHIN.

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5.2.3 Regional Clinical Leadership role of the academic health sciences centre/network in London

Proposed Future State - role of the academic health sciences centre/network

London Health Sciences Centre

LHSC is a tertiary acute care teaching hospital and part of an academic health sciences centre/network and as such its role includes the training of health care professionals in respiratory acute care and treatment, clinical research into respiratory diseases and treatment, dissemination and promotion of evidence-based care standards, knowledge translation and collaboration with other acute and chronic respiratory care centres in Ontario and across Canada. Their role also includes the training and education of community-based professionals and service providers in best practices and standards-based care as it applies to the clinical management of respiratory care.

LHSC staff and physicians have developed and built particular expertise in the respiratory care and treatment of adults living with chronic mechanical ventilation from an acute care perspective.

As a regional centre of clinical excellence for acute and chronic adult respiratory care this role would include but not be limited to:

- Providing clinical direction and expertise to others who serve this population
- Delivering both clinical training and education to caregivers and other service providers
- Serving as an academic centre for both education and research
- Working in partnership with other hospitals in the South West LHIN especially with Level 3 ICUs who serve this same population
- Playing a leadership role in the development and use of clinical standards and protocols

This role would be addressed through the CMV Interprofessional Care Team. [See Figure 9 for details.](#)

St. Joseph's Health Care London – Parkwood Hospital

St. Joseph's is also part of the London-based academic health sciences centre/network. Parkwood Hospital as a stand-alone non-acute care hospital has important experience and expertise in working with and serving adults with chronic mechanical ventilation needs – both NIV and IV from a complex continuing care perspective. It is proposed that Parkwood Hospital is well positioned to provide a leadership role in supporting the use of best practices within non-acute settings.

Recommendation 5.2.3.1

As there is an academic health sciences centre/network involved in the partnership to support adults living with chronic mechanical ventilation, it is recommended that LHSC and St. Joseph's, in partnership with other hospitals and community-based organizations serving adults with chronic mechanical ventilation take the lead in:

- **The teaching of health care professionals in the care and support of adults living with chronic mechanical ventilation in community settings**
- **Research into long-term care and support of these adults**
- **Training and education of community-based professionals and service providers in best practices**
- **Development and application of standards-based care pathways that will support people during transitions in care, sustain them in a community setting, and enhance their quality of life.**

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5.3. Community Health and Supportive Care Services

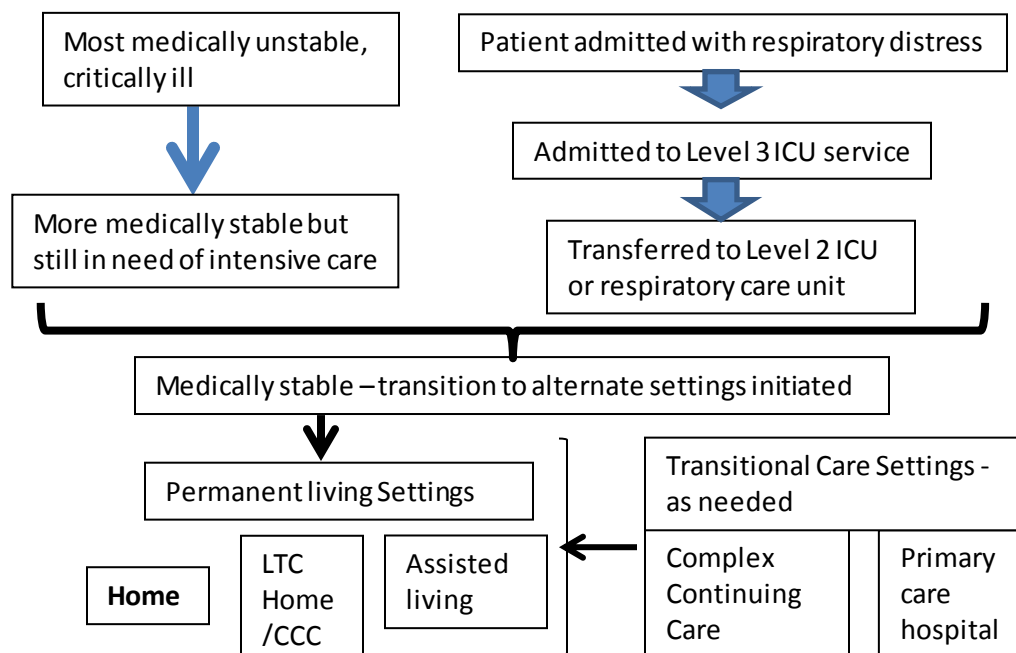
System Overview

One of the objectives of this project is to design a system of health and supportive care services that will enable people dependent on mechanical ventilation to live in the least restrictive home-like environment possible. The goal is to have people living with chronic mechanical ventilation living in the community, and only 'living' in a hospital environment for limited periods or only in exceptional circumstances.

The systems model recognizes that all people living with chronic mechanical ventilation require on-going health and supportive care services. These services range from providing ongoing care 24x7, to providing daily or periodic support on a routine or as needed basis. In addition, the combination of health and supportive care services needed by each person and family will vary by individual and change over time.

Community-based services include a wide range of health and supportive care services provided outside of a hospital setting. Because the goal is to have as many adults living with chronic mechanical ventilation living in the community as possible, the range and combinations of community health and supportive care services are more diverse than hospital-based care.⁹

Figure 6 Patient/client Flow from hospital to permanent living setting - home



5.3.1. Living at Home

System Overview

In many cases, people living with mechanical ventilation support are living at home and family members are their primary caregivers. This is certainly the case for children and adolescents and it is true for adults as well. If a life-long condition is involved then parents often continue to play an active caregiving role as their children age. If the condition involves adult onset then the primary caregiver might be a spouse or other family member. As can be appreciated this is a significant responsibility for family members who are serving as the primary day-to-day caregivers and not one that is taken on lightly. The on-going care role can be taxing and caregivers need periodic support and relief for their own health and well-being. Respite care, whether that takes the form of someone coming

⁹ Excerpt from *Long-term Mechanical Service Inventory Program Final Summary Report*, July 31, 2008, MOHLTC, Priorities for Care and Services (p. iii) **Increase the capacity for and choice of community living.** Twenty-two percent of ventilator-assisted individuals in hospital were deemed eligible for community living. The lack of available and appropriate community care settings is a major barrier to timely discharge from hospital and contributes to reduced quality of life for ventilator-assisted individuals.

into the home for a period of time; whether the person living with mechanical ventilation lives somewhere else for a temporary period of time; or whether they attend an adult day program – these options all provide temporary relief from the on-going responsibilities of the primary caregiver. The role played by family members is a distinct support and care role that is important to respect and acknowledge – it is also essential to people being able to live in their own homes.

As noted in the Section 4 – Data and Demographics – most people living with chronic mechanical ventilation, especially those using non-invasive ventilation (NIV) are living at home and will continue to do so. The ability to sustain living at home is subject to a number of complex factors. It can include medical, social, physical, emotional and financial factors.

The following factors that impact on being to support living at home are taken from a February 2012 report of the Canadian Agency for Drugs and Technologies in Health called “Transitioning Long-Term Ventilator-Dependent patients Out of the Intensive Care Unit – An Environmental Scan”¹⁰

- The patient’s and when applicable family’s level of motivation and willingness to accept risk factors with living at home
- The availability of trained, reliable family or caregiver support, with availability of backup options
- The availability of a physician in the community familiar with LTV patient care
- Financial considerations
- Ensuring that patient mobility issues (e.g. wheelchair modifications for a ventilator), home-related accessibility factors, and safety considerations (availability of backup power generation, home inspection by Fire Department) are addressed

Another key ingredient for success is training of family members so they can monitor, trouble shoot and intervene as necessary. The following is from the same Environmental Scan report quoted above.

The majority of programs or centres surveyed indicated that they provide training for patients and their families and/or caregivers, as well as staff, when applicable to their programs.

The majority of programs were very comprehensive with their training, with many indicating that they covered the following major topics in their training sessions:

- tracheostomy care
- suctioning
- manual bagging
- emergency procedures
- equipment maintenance and cleaning
- ventilator and other equipment troubleshooting.

The report goes on to identify a number of system processes and supports required for implementing a transition program. Included in the list is the following statement:

- Availability of comprehensive training for patients, families, and/or caregivers both initially before discharge, and on a continuing basis thereafter
- Ensuring that health care professionals, family, and/or caregiver, as well as facility-related support issues have been established, addressed, and confirmed as being available prior to patient transitioning to an alternate care site
- Strong community home care program support availability for patients transitioned to their homes

The message is clear. Families can be very successful in supporting their loved one at home but it is conditional on a number of essential factors and services being in place to support educate and train families in their role.

The following is a profile of the living-at-home option and a summary of the associated health and supportive care services that are essential to supporting a person living at home on an on-going basis. This is in addition to whatever hospital-based services they might access. This covers the situation where a person with chronic mechanical ventilation needs is stable enough to live in their own home with day-to-day care being provided by

¹⁰ A complementary set of information can be found in Appendix C under the title: – Canadian Thoracic Society - clinical practice guideline Canadian Respiratory Journal (Vol. 18 No 4), “Home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline” July/August 2011.

family members, and occasional use of community health and supportive care services. The person may also have to access community support services, provided outside of the home, on a daily basis.

5.3.2. Services provided by family members as primary caregivers

System Overview

The family member(s) serving as the primary caregiver(s) with the support of both health and supportive care services needs to be able to provide the following range of care:

- To provide the day-to-day health care needs including the on-going respiratory-related needs of the person with chronic mechanical ventilation
- To assist with activities of daily living
- To provide the day-to-day supportive care needs of this person
- When necessary to identify and arrange to receive at-home or community nursing and other allied health related care services that the person might need
- To address periodic respiratory-related needs of the person with chronic mechanical ventilation through the services of a community respiratory therapist
- To arrange and support the person's integration and engagement in community life
- To arrange and support the person's family and friends participation in their lives
- To work closely with health and supportive care services to facilitate and support the person's transition into other settings as needed
- To support the person getting access to primary health care
- To advocate with and for their family member

The essential role family member's play as primary caregivers is acknowledged and they are accepted as full members of the care team bringing particular insights, skills and knowledge to the situation. Meeting their support needs is also key to sustaining their on-going caregiving role.

Recommendation 5.3.2.1

It is recommended that family members receive comprehensive education, training and on-going support to sustain their role as primary caregivers.

5.3.3. In-home support services

System Overview

To live safely at home, a person dependent on mechanical ventilation needs periodic access to a core set of community health and support services.

These services include:

- At-home or community based medical, nursing and other allied health related care services including respiratory and physiotherapy
- A Family Physician who is prepared to take patients who are dependent on mechanical ventilation
- Access to respite care¹¹ and day program services

The following set of in-home support services are defined as the core set of health care services required to support adults living with chronic mechanical ventilation – to live at home as long as they are willing and able to do so.

- **At-home or community based medical, nursing and other allied health related care services including respiratory and physiotherapy**
- **Access to primary health care services**
- **Access to respite care and day program services**
- **Access to scheduled respiratory care follow-up**

¹¹ Excerpt from *Long-term Mechanical Service Inventory Program Final Summary Report*, July 31, 2008, MOHLTC, Priorities for Care and Services (p. iii) **Provide respite for caregivers**. When ventilator-assisted individuals live with their family, the burden of care is often overwhelming for the caregivers. Many families believed they could have cared for their children or spouses in the home for a longer period of time if they had had access to respite. The preference is for in-home respite, although inpatient respite is sometimes needed for extended family absences.

Implications for the South West LHIN

Proposed Future state – in home support services

Most adults living with chronic mechanical ventilation especially those using NIV are currently living at home and will continue to do so. The South West CCAC, like all CCACs in Ontario has a primary mandate to support people living at home, to assess people for their personal health and support needs and to contract for the provision of in-home personal health and support services. The complexity of needs being addressed in the home is increasing and the level and sophistication of care and support that needs to be provided is therefore also increasing. This is especially true of people who need on-going and continuous, rather than time limited support. Like every other sector of health care system chronic diseases and conditions are leading the CCACs to respond by changing their model of service delivery and this is especially true for people who have complex conditions and are medically fragile.

As part of an Ontario-wide change on the part of the 14 CCACs, steps are currently being taken to reorganize the caseload of CCAC care coordinators according to the levels of service needed by different client populations. As part of this broader change the South West Community Care Access Centre has organized itself to address the complex and on-going needs of clients such as adults living with chronic mechanical ventilation and are doing this by establishing complex care coordinators¹² who either have or will develop expertise working with this and related populations of clients. This will allow the same coordinators to be involved with the client regardless of their circumstances and needs. This will fill an important gap in the continuity of community and in-home care for these individuals.

The South West Community Care Access Centre needs to continue to assume a leadership role with respect to the coordination of in-home support services in partnership with other organizations that serve adults living with chronic mechanical ventilation.

Recommendation 5.3.3.1

It is recommended that the South West CCAC identify clients living with chronic mechanical ventilation and related conditions as a primary client group for its Complex Care Coordinators and specifically recruit or train staff so they can develop the necessary clinical expertise and experience to work with this client population. Complex Care Coordinators are in a position, on an as-needed basis, to engage additional resources such as the intensive home care team – especially when transitions in care are being planned and implemented.

Recommendation 5.3.3.2

It is recommended that all hospital inpatients on NIV and IV be referred to the CCAC and that a standardized screening tool be developed and used to assess whether outpatient NIV patients need to be referred to the CCAC.

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5.3.4. Respite Care Services

System Overview

Respite care services are provided for a temporary period of time to adults dependent on chronic mechanical ventilation who are living at home, or to family members who are their primary caregivers. Respite care is either provided in the home by supportive care professionals or off-site by a designated respite care provider organization.

The ability to access respite care is essential to providing needed support under a range of circumstances. They include but are not limited to the following:

- When the primary caregiver is ill, injured, or otherwise unable to provide the care required;
- When the primary caregiver needs to be away from home for a period of time including vacation time; or
- When the person living with chronic mechanical ventilation cannot remain in the home for a period of time.

Respite care can be delivered in a variety of forms.

¹² See Appendix B for details concerning the CCAC Client Care Model and the population-based approach to segmentation of client services for Ontario's CCACs.

- Provided on 24/7 basis for a planned period of days when the primary caregiver will not be available to provide the needed day-to-day care. This can be delivered either in the home or by re-locating the person dependent on mechanical ventilation to a designated respite care location.
- Provided periodically in the home, on a planned basis, for a defined number of hours to allow the primary caregiver to leave the home and do other things.
- In an emergency situation when there is need to additional supportive care due to an unexpected event, such as a sudden illness or injury of the primary caregiver. Such respite care has to be arranged and implemented quickly and without warning on a 24/7 basis.

Regardless of the setting, supportive care staff who are providing respite care need to have the resources, training, supports and ability to successfully address the short term needs of the individual and to do so in a way that addresses the special needs of the individual involved. It is the transfer of responsibility for care that needs to be carefully and thoughtfully planned and implemented. In this context it is essential to the quality and continuity of care that plans for both planned and emergency respite care be put in place so that when they need to be activated, everyone involved has a clear understanding of how it will be coordinated and implemented.

In addition to the direct services provided through respite care, it also provides an opportunity to build relationships with the client and family and to gain an understanding of what the longer term needs of the client might be, including transitions from home to an alternate community setting.

Implications for the South West LHIN

Current State – respite care

Although there is some respite care available through the CCAC throughout the South West LHIN it is limited and there is a critical service gap in terms of supporting families and adults living at home through both respite care and adult day programs where respite care is a secondary outcome.

Participation House Support Services based in London has recently been funded by the South West LHIN to support overnight respite care for young adults with complex needs. These funds will help to support the respite care needs of a relatively small number of people, including individuals living with chronic mechanical ventilation.

St. Joseph's Parkwood Hospital is also a facility that has the capability of providing overnight respite care in its complex continuing care unit. This capability could be realized through the use of the recommended 'flex beds'.

Elsewhere within the South West LHIN there are few respite care resources specialized in serving this population through out-of-home respite care.

Long-Term Care homes have respite care beds available for short stay purposes and are a potential setting for overnight and short term respite, especially for CMV-NIV clients.

There is a need to fully understand the number of people living at home with their families who could benefit from additional in-home as well as out-of-home respite care. Once this information is known local solutions need to be developed that will provide viable, sustainable options for families and their loved ones.

As an illustration, current estimates based on information presented in this paper put the number of adults living with CMV in the community at about 200. Most, but not all are living at home. Future projections estimate that this number will grow by 34 people per year. This gives some indication of what the overall or gross need might be. It will only be through individual case reviews that the net need can be confirmed.

Proposed Future State – respite care

Recommendation 5.3.4.1

It is recommended that all primary caregivers who are supporting an adult living with chronic mechanical ventilation at home be assessed by the South West CCAC for their eligibility to receive respite care services to support their on-going care and support role.

Recommendation 5.3.4.2

It is recommended that the South West CCAC take a lead role in defining the respite care needs of CCAC clients living with chronic mechanical ventilation and take the necessary steps to coordinate and expedite access to in-home, out-of-home and overnight respite care – both planned and emergency.

There is a need to be able to plan for respite care services for this special needs population on a system-wide basis and therefore the information collected by the CCAC should be used to assess the overall need for these services throughout the South West LHIN and to develop multi-year proposals for the development of in-home, out-of-home and overnight respite care, both planned and emergency.

5.3.5. Adult Day Programs¹³

System Overview

For persons who are living in the community and do not have access to day programs where they reside, adult day programs offer an opportunity for them to engage in community life in a safe and supportive community setting. In terms of the Adult Day Program, here is a description of its role.

- To provide persons with a recreation and therapeutic environment that provides opportunities for personal development and stimulation, social development and engagement with others, outings etc. – typically this environment serves elderly people who are frail but they also serve people with different special needs, Alzheimer's and acquired brain injury for example.
- Although not the primary purpose of Adult Day Programs, for a person living at home attending an adult day program provides their primary caregiver with a predictable day-time break from their on-going responsibilities. In this context regular attendance at an adult day program serves a similar role as attending school does for children with special needs and their parents.

People dependent on CMV who are living in the community need to have access to a specialized adult day program or to a day program with skilled staff who are capable of providing them with a rewarding adult day program experience when other daily living options are not available or suitable. The word “specialized” is used because in general adult day programs are designed for frail seniors, not for people living with chronic mechanical ventilation. These programs need to be accessible and therefore located close to where persons dependent on mechanical ventilation live whether they are living at home, in Assisted Living, in Long-Term Care Homes or elsewhere.

Implications for the South West LHIN

Current State – adult day programs

The current Access to Care project of the South West LHIN – and its Assisted Living/Supportive Housing and Adult Day Program component has the following mandate:

The mandate of the initiative:

- Realign and enhance community capacity in assisted living, supportive housing and adult day programs to meet the needs of our region.
- Implement the Community Care Access Centre's (CCAC) expanded role to ensure easy and equitable access to these important services for all clients.
- Implement a common assessment tool for Community Support Services, to ensure that all clients receive consistent, high quality assessment.

Among the benefits of reaching these goals:

- More clients will be able to live safely and comfortably in the community.
- More clients will experience easy and seamless transitions across the health system.
- Decreased Emergency Department visits and hospitalizations.

¹³ South West LHIN Access to Care project defines [Adult Day Programs](#) as follows: “Planned social and recreational activities, meals, assistance with the activities of daily living and minor health care assistance; e.g. monitoring essential medications. These activities are provided in a congregate setting, provide respite care to caregivers and are likely to be one of a basket of services that the client is receiving.”

This is exactly what is needed for adults living with chronic mechanical ventilation and therefore this population should be made an explicit part of this project's mandate.

A recent report (April 17, 2013) of the South West LHIN's Access to Care project focused attention on special populations¹⁴. Youth transitioning to adults who are Medically Fragile/Technology Dependent (MF/TD) were defined as being within scope of this project and as an identified special population. Both tracheotomy and ventilation care are listed as part of a much larger list of services being provided. A total of 37 people were listed as being on the CCAC caseload and as being youth transitioning to adults who are Medically Fragile/Technology Dependent (MFTD). The age range captured were persons 15-21. These 37 people are living throughout the LHIN as follows: Grey Bruce (5), Huron Perth (8), London/Middlesex/Elgin (9) and Oxford (15).

The report goes on to say "Special Population funding has not kept up with demand or inflation, creating significant waitlists for these groups and upcoming deficits particularly in Assisted Living/Supportive Housing". The South West LHIN has responded by making a number of investments including overnight Respite and Day Program space increases for the MF/TD population in London (\$525,000). The report calls for continued investment of funds to support these special populations.

The 2013 report also identifies transportation and financial cost as access issues:

Transportation

The need for transportation was reinforced as a significant barrier to service, particularly for the ADPs, which rely on transportation as a means of ensuring access to care for clients. Case managers, clients and service providers in every focus group session identified this as a key service in ensuring successful service initiation.

Cost is a considerable barrier, especially for those in rural areas who often travel up to 25 km to attend a program, and who are required to travel to urban centers for medical (and specialist) appointments. This issue will be compounded as transportation costs continue to increase and program resources become more limited.

As noted above, this is a significant gap, acutely felt by families whose children are transitioning to adult services as they lose access to the education system and their transportation services.

In many cases special transportation services are needed to transport people to these programs and this requires both financial and skilled staff support. Skilled staff who know and understand the needs of the individual client need to be available during the transportation time as well as during the Adult Day Program.

Participation House Support Services has recently been approved by the South West LHIN to receive operating funds to provide day programming for young adults with complex needs. These funds also included one-time funds to purchase a vehicle to transport participants. These funds will help to support the day program needs of a relatively small number of people, including individuals with chronic mechanical ventilation.

There is a need to fully understand the number of people living at home with their families throughout the South West LHIN who could benefit from attending an adult day program. As noted in the April 17, 2013 report, "There is a need to implement new robust data collection and evaluation processes to leverage in making informed decisions about Special Populations going forward".

The South West Community Care Access Centre, as part of its expanded mandate has responsibility for determining eligibility and managing the wait list for persons identified as benefitting from attending an Adult Day Program and the South West LHIN has the mandate to provide financial support for the on-going operations of adult day programs.

The intended benefits to be realized from the South West LHIN's Access to Care project's Assisted Living-Supportive Housing and Adult Day Program work are as follows:

- More clients will be able to live safely and comfortably in the community.
- More clients will experience easy and seamless transitions across the health system.
- Decreased Emergency Department visits and hospitalizations.

¹⁴ [Assisted Living/Supportive Housing/Adult Day Programs for Special Populations Final Report, April 17, 2013](#)

This is exactly what is needed for adults living with chronic mechanical ventilation and therefore this population should be made an explicit part of this project's mandate.

Proposed Future State – Adult Day Programs

Access to suitable adult day programs can make a significant contribution to the life of an adult living with chronic mechanical ventilation and to their families.

In the future, adult day programs need to be available and accessible throughout the South West LHIN to adults living with chronic mechanical ventilation. In most cases these will be integrated programs for adults with special needs – and as noted in the South West LHIN report, they have to be designed for a younger, adult population, not for seniors. Although the South West CCAC does not run adult day programs they will play a key role in helping to identify needs and coordinate access to the services that do exist.

As noted earlier if it is assumed that there are 200 adults with CMV living in the community and an annual increase of 34 people per year this gives some indication of what the overall or gross need might be. It will only be through individual case reviews that the net need can be confirmed.

Recommendation 5.3.5.1

It is recommended that adults living with chronic mechanical ventilation in the community and at home with the support of primary caregivers be assessed by the South West CCAC for their eligibility to participate in adult day programs which are suitable and have staff skilled in being able to meet the personal and social needs of this population.

Recommendation 5.3.5.2

It is recommended that the South West CCAC take the lead in monitoring the use and need for adult day programs by the CMV population and from a systems perspective use this information to support the mandate of the proposed system oversight committee to assess the service needs of this population throughout the South West LHIN.

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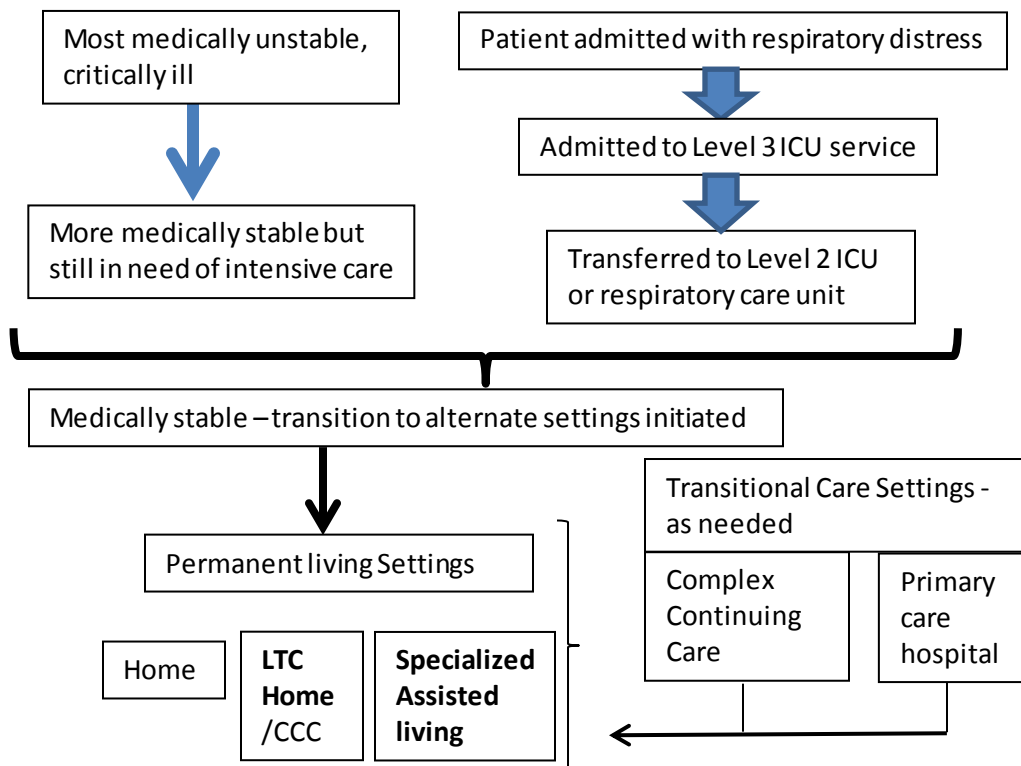
5.3.6. Specialized Community Services

System Overview

For families, the ability, capacity and stamina to provide on-going care to their adult family member varies. This might be a function of their own situation and support but it can also be attributed to the degenerative nature of the chronic disease. As such, the ability to transition the family member from home to an alternate community setting is critical.

For a variety of reasons, not everyone is able to live at home, but at the same time they may not require the sophisticated health care services such as those provided in a hospital-based acute or complex care environment. In these cases, alternate community settings are most suitable. While different types of living settings are possible, the number and type of settings that decide to make their services available to this population is quite limited because of the combined complexity of the health and supportive care needs of people who are dependent on CMV, especially those who use invasive ventilation.

Figure 7 Patient/client Flow from hospital to permanent living setting – LTC & Specialized Assisted Living



For people who are living with non-invasive ventilation there are more options. As an example, people using NIV can be supported and live in supportive housing or a retirement home if funds allow and their overall health is not compromised in other ways. People in this sub-group can be supported in an Assisted Living or Long-Term Care Home if they have other health and supportive care needs that required more sophisticated health and support care services.

The two specialized community settings are Assisted Living and Long-Term Care Homes. The general characteristics of each of these services as they apply to adults living with chronic mechanical ventilation are summarized below.

5.3.7. Specialized Assisted Living Housing

System Overview

Specialized Assisted Living Housing¹⁵ is a specialized community option that focuses on providing “services that support people with special needs who require services at a greater frequency or intensity than home care but without the medical monitoring or supervision that would be provided in a long-term care home.”¹⁶ These services as they apply to adults living with CMV are provided in custom-designed homes with 24/7 supportive care provided by trained specialists. Assisted Living Housing is able to support individuals with multiple chronic conditions and disabilities who do not require ongoing health care by regulated health care professionals.

For those organizations that opt to provide services and develop the necessary expertise to serve this population, the following is a description of their role.

¹⁵ The term Assisted Living is also used to describe services to assist people to live in their own home but in this context the term is being used to reflect a community housing option with full-time staff support, hence the term Assisted Living Housing.

¹⁶ South west LHIN Access to Care project, “Access to Care Adult Day Program, Assisted Living and Supportive Housing Definitions”
http://www.southwestlhin.on.ca/uploadedFiles/Public_Community/Current_Initiatives/Access_to_Care/Access%20to%20Care%20Adult%20Day%20Programs.%20Assisted%20Living%20and%20Supportive%20Housing%20Definitions.pdf

Proposed Specialized Assisted Living Housing role

- To provide a permanent, safe home environment in which a person with chronic mechanical ventilation can live on an on-going basis
- To support either invasive or non-invasive mechanical ventilation (some may offer NIV only, others both)
- To address the on-going respiratory-related needs of persons with chronic mechanical ventilation
- To have 24x7 staffing in the home who provide the support and care required for daily living
- To coordinate and support people getting access to primary and hospital-based health care
- To support the person's integration and engagement in community life within and outside the assisted living environment including transportation and information services
- To support the person's family and friends participation in their lives
- To work closely with other organizations to facilitate and support the person's transition into Assisted Living and transitions to other settings as needed
- To work collaboratively with other organizations and with the patient/client and family to determine the most appropriate transition, when transition to another setting is deemed appropriate
- To provide respite care for primary caregivers when individuals with chronic mechanical ventilation are living in the community at home

5.3.8. Long-Term Care Homes

System Overview

Long-Term Care Home's include many components of Assisted Living Housing with the addition of on-site health care services from nurses and other health care professionals. If a Long-Term Care Home decides to serve adults living with chronic mechanical ventilation, the following is a summary of their role.

Proposed LTC Home role

- To provide a permanent, safe environment in which a person with non-invasive chronic mechanical ventilation can live on an on-going basis. This would include persons whose primary respiratory dependency is the need for tracheostomy care
- To address the on-going respiratory-related needs of persons with chronic mechanical ventilation
- To have 24x7 staffing available to support their activities of daily living
- To address the primary health care needs of the person
- To support the person's integration and engagement in community life within and outside the LTC Home
- To support the person's family and friends participation in their lives
- To work closely with other organizations to facilitate and support the person's transition to other settings as needed
- To work collaboratively with other organizations and with the patient/client and family to determine the most appropriate transition, when transition to another setting is deemed appropriate
- To provide respite care for primary caregivers who are supporting older adults living with NIV in the community at home

Implications for the South West LHIN

Current State - Assisted Living and Long-Term Care Homes

The same South West LHIN report that addressed Adult Day Programs (2013 report) also addressed the need for Supportive Housing and Assisted Living (AL). As with the Adult Day Programs the primary focus of these services is typically high risk seniors, not adults. The report defines Assisted Living as a non-building based model and Supportive Housing as a building-based model to support independent, community living. In both cases the focus is on the services being provided, not the location as health care funds services, not housing. This is spelled out in more detail below.

The new Assisted Living for High Risk Seniors Policy, 2011 enables the de-linking of AL services from social housing/buildings and creates the opportunity for the development of community hub models that support high risk seniors to remain in their own homes.

There are approximately 40 programs (multiple programs/buildings within a city were counted as one) delivered by 16 providers across the South West LHIN. These numbers include the special populations. There are 25 seniors' programs delivered by 12 organizations.

The report profiles the current availability of Assisted Living spaces as follows: Elgin (85), Grey-Bruce (133), London-Middlesex (136), Oxford (62) and Huron-Perth (65).

Special populations currently being served include: adults with physical disabilities, people living with HIV/AIDS, people with Acquired Brain Injury and adults with chronic mechanical ventilation (through Participation House Support Services in London).

At the present time Participation House is the primary community agency that provides residential support to adults living with chronic mechanical ventilation and it has recently received operating funds from the South West LHIN to expand the number of people it can serve. This role on the part of Participation House is a very valuable one for people who need the level of care they provide.

Participation House is the only community-based supportive services agency that offers homes to adults with chronic mechanical ventilation in the South West LHIN area.

At the present time Long-Term Care Home facilities do not usually serve this population, although they do serve many people who require respiratory support, primarily oxygen. There are some homes that do have residents living with CMV-NIV although current information is not readily available to document how many.

Like Participation House, any Long-Term Care Home facility that decides to serve this special needs population needs to do so being prepared to make a long-term commitment to serve this population and to use a partnership model. It is proposed that Long-Term Care Homes be designated as specialized facilities to serve this population and that geographically they be given a multi-community mandate.

As the CCAC is the gatekeeper to accessing LTC Home services, and with its expanded role, also Supportive Housing, Assisted Living and Complex Continuing Care it is proposed that their Complex Care Coordinators are in an excellent position to assess the appropriateness of placing an adult with chronic mechanical ventilation in the most appropriate Long-Term Care Home or alternate setting, provided they make this determination in partnership with the other organizations that also serve adults living with chronic mechanical ventilation.

In preparing for the future there is a need to understand the need for different forms of community residence settings when living at home is not a viable or sustainable option and to develop options.

Immediate steps should be taken to include adults living with chronic mechanical ventilation within the mandate of the South West LHINs Access to Care - Assisted Living/Supportive Housing and Adult Day Program initiative.

Proposed Future State – Specialized Assisted Living and Long-Term Care Homes

On an on-going basis it is essential that steps be taken to support families as much as possible but when this is no longer a viable option, to have alternatives available. This transition may need to be planned well in advance given the complexities involved – up to several years. Being proactive requires early conversations with families to understand their long-term plans and wishes. While the CCAC has a primary responsibility to undertake this on-going needs assessment, they do not have the mandate to create the housing spaces themselves. In general, the cost of building community housing falls outside the mandate of the Ministry of Health and Long-Term Care although they do fund the services provided in these settings.

Assisted living housing as described should focus on meeting the needs of adults. Long-Term Care homes are in place to serve the needs of seniors. There may be circumstances in which it might be suitable to place an adult living with chronic mechanical ventilation in a LTC home for specific reasons, especially if there is a special unit for adults – but generally it would not be an age appropriate setting. Elderly persons living with CMV-NIV would, of course, be most suitable candidates for such a setting. The options considered and made available need to address the needs of the individual and at the same time respect their personal values and priorities.

The South West CCAC in its newly expanded role will play a key role in two ways: One - coordinating access to these community services and Two - being able to monitor and assess the need for these community settings from a system-wide perspective.

Recommendation 5.3.6.1

It is recommended that throughout the South West LHIN, the Complex Care Coordinators of the South West CCAC take the lead in assessing the appropriateness of having an adult living with CMV live in Supportive Housing, Specialized Assisted Living, a Long-Term Care Home or Complex Continuing Care, and that they do so in partnership with the other organizations that are currently serving this population.

Recommendation 5.3.6.2

It is recommended that the South West CCAC take the lead in monitoring the use and need for Supportive Housing, Specialized Assisted Living and Long-Term Care Home by the CMV population and from a systems perspective use this information to support the mandate of the proposed system oversight committee to assess the service needs of this population throughout the South West LHIN.

Having an appropriate setting in which to live is key to being able to support people in the community and to reduce the risk of hospitalization. While other options might be developed in the future, the two that are currently in place are Assisted Living Housing and LTC homes. LTC homes as noted should focus on developing the ability to support older adults who are using non-invasive ventilation. Assisted Living Housing should focus on adults using both NIV and IV.

Specialized Assisted Living Housing should be accepted as the preferred living settings for adults living with chronic mechanical ventilation (NIV and IV) when they have needs that can best be addressed through Assisted Living and living at home is not an option.

Recommendation 5.3.6.3

It is recommended that designated Long-Term Care Homes be accepted as the preferred living settings for older adults living with CMV-NIV when they have needs that can best be addressed through living in a Long-Term Care Home and living at home is not an option.

Recommendation 5.3.6.4

It is recommended that a community support services agency with developed expertise in supporting residents with chronic mechanical ventilation needs assume the lead in establishing and/or supporting other services to establish housing to meet local needs of this population within the South West LHIN.

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5.3.9. Community Respiratory Therapy Services¹⁷

System Overview

Ready and on-going access to respiratory therapy services is an essential service for people using chronic mechanical ventilation; as vital as having access to the expert medical direction of a respirologist. For people being treated and staying in hospital, respiratory therapy services are available on site. In the community this is not the case. Visiting respiratory therapy services is the mode through which this service is provided. The most common approach is to do some work directly with the client but most often it involves teaching, coaching and supporting the primary caregiver and home-based support service providers so they are able to address the respiratory needs of the client on an on-going basis and in the moment.

In the community the role of respiratory therapists can be summarized as follows:

- To provide clinical support and on-going education to caregivers and interprofessional team members
- To monitor the effectiveness of the mechanical ventilator and to report findings to a respirologist for medical direction as needed
- To report findings, follow-up action and recommendations to other care providers
- To provide transitions support when a person needs to move to another setting (for respite care for example) or when changes in the life status of the individual, including palliation, need to be made
- To introduce and educate primary care providers and caregivers about cough assist technology and techniques¹⁸.

¹⁷ For more information see the College of Respiratory Therapists of Ontario web site <http://www.crto.on.ca/>

¹⁸ Canadian Respiratory Journal, Vol 18 No 4 July/August 2011. Home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline. "Adequate airway clearance may be the single most critical therapeutic intervention that prevents acute respiratory failure, undesired intubation and tracheostomy in patients at risk for using NIV." p. 200.

In 2010 the College of Respiratory Therapists of Ontario published a report “Optimizing Respiratory Therapy Services A Continuum of Care from Hospital to Home, June 2010 Final Report” based on a community RT model of care. The report described the role of the participants in the project as follows:

Acute care RTs — provided direct patient care for in-patients requiring all types of ventilation and airway management. Together with the community RTs, their roles and responsibilities in this project included: identifying patients who are at-risk of becoming ventilator-dependent and recommending weaning strategies; assessing patients who are already on LTV to determine if they are able to transition into the community; coordinating with resources both inside and outside the acute care facility to assist in the placement or repatriation; coordinating the initial education for the patient and caregivers.

Other acute care Health Care Providers (HCPs) such as physicians (MD), nurses, occupational therapists (OTs), physical therapists (PTs), dieticians, and social work (SW) were involved with the discharge of the patient.

Community RTs — roles and responsibilities included: collaborating with the acute care team, the patient, his/her family and other caregivers to determine the best care plan for each individual; transitioning patients into the community (organizing trial runs, home respiratory equipment set up, education); instruction and training in the home setting; 24/7 support at home (clinical, equipment, initial and ongoing education, risk management); instruction of adjunct therapy (inhaled medication, pulmonary function, oxygen) and; communication with patients’ physicians and other HCPs.

Patient’s caregivers e.g. family, PSWs — contributed toward the individual care plan and subsequent care of the patient in the community (together with the patient and other HCPs involved with his/her care). They identified any barriers and challenges and worked together with the community RTs and other HCPs to overcome them. They were the communication link between the patient and the HCPs.

Other HCPs such as MDs and nurses (RN and RPN) helped provide medical care to the patient while they were in the community. OTs and PTs were involved on an as needed

Learning of utmost importance is individuals with complex respiratory needs benefit measurably from adequate RT services in achieving independence & quality of life in the community. This can be accomplished by utilizing the existing competencies of RTs already working in the community setting & using a consistent process & tools that are evidence-based & practice-driven, all within an interprofessional team. In addition, this process allows the system to be more efficient because there is reduced LOS & increased availability of beds within acute care facilities.

Effectively caring for this patient population in the community has resulted in a reduced demand on the healthcare system, such as decreased physician visits &/or readmissions to hospital.

Although we learned patients lead a better QOL in the community, we also noticed the burden placed on the family was very high. Families & caregivers are willing to make sacrifices in order to have their family member in the community setting. The objectively measured burden is financial: the lack of funded resources available to the patient in the community versus in acute care. In the acute care setting, all equipment, staff, rehabilitation, diagnostics & accommodations were available at no cost to the family. However, once they are discharged into the community, the amount of financial support available for these individuals varies widely & often requires families to self-pay to cover necessary expenses.

As an additional reference point the following list is taken from a brochure from British Columbia’s Provincial Respiratory Outreach Program (PROP). It is widely acknowledged to be one of the best community RT support services in Canada. It is organized as a province-wide program and as the following list demonstrates it includes RRT services, RT equipment and education services

- Through our 24-hour On Call service, a PROP Registered Respiratory Therapist (RRT) is available around the clock to provide individualized information and advice

- We have an equipment pool of ventilators, BPAP¹⁹s and auxiliary equipment, as well as an inventory of supplies and parts.
- RRTs visit clients in their homes throughout BC to provide individualized care. Each client receives at least one visit per year.
- We have an education program that provides workshops to clients, families and caregivers, and health professionals.
- Our Biomedical Engineers maintain and repair all respiratory equipment for clients, including mounting ventilators on wheelchairs. We ensure that equipment used by our clients is available, safe and operational.
- Our team works with acute care units to transition ventilator-dependent clients into the community. We tailor the discharge planning process to fit with the mix of services required by individual centres in the various health regions.
- We have developed a wide range of educational materials to assist and inform clients.
- Our team has developed a unique level of expertise in providing the complex supports needed by people living with ALS.

The following chart has been developed by respirologist Dr. David Leasa, London Health Sciences Centre to profile the role community respiratory therapist during transitions.

Table 6 Chronic Mechanical Ventilation and Community Respiratory Therapy Services
(Credit to Dr. David Leasa, Respirologist, LHSC)

Legend

LTMV = Long Term Mechanical Ventilation
 CMV = Chronic Mechanical Ventilation
 CCAC = Community Care Access Centre
 RRT = Registered Respiratory Therapist

Transition	RRT Home Services Provided	Frequency	Reporting
From hospital to LTMV care at home or assisted life in the community	<ul style="list-style-type: none"> - Ensure safe setup of the ventilator equipment in the home setting - Ensure safe transfer of the ventilator prescription/respiratory care plan at hospital discharge - Reinforce the transition plan respiratory care teaching for the patient/family/caregivers 	Daily visits X 5; then monthly X 3 visits; then as requested by the acute care CMV team	<ul style="list-style-type: none"> - CCAC - acute care CMV team
From community LTMV back to acute critical care	<ul style="list-style-type: none"> - Available to assess worsening patient symptoms to ensure proper equipment functioning (prevent inappropriate transition, if possible) 	On-call availability	<ul style="list-style-type: none"> - CCAC - acute care CMV team
From pediatric to adult LTMV	<ul style="list-style-type: none"> - Ensure safe transfer of the ventilator prescription/respiratory care plan at transition - Reinforce the respiratory care teaching or the patient/family/caregivers 	Initial visit; then as requested by the acute care CMV team	<ul style="list-style-type: none"> - CCAC - acute care CMV team - Paediatric care team

¹⁹ From Wikipedia: **Bi-level Positive Airway Pressure (BPAP)** is a [continuous positive airway pressure](#) (CPAP) [mode](#) used during noninvasive positive pressure ventilation. It delivers a preset inspiratory positive airway pressure (IPAP) and expiratory positive airway pressure (EPAP). BPAP can be described as a continuous positive airway pressure system with a time-cycled or flow-cycled change of the applied CPAP level.^[1] CPAP, BPAP and other non-invasive ventilation modes have been shown to be effective management tools for [chronic obstructive pulmonary disease](#) and acute respiratory failure.^[2] Another term for bi-level positive airway pressure, and the term becoming increasingly adopted by the medical community, is non-invasive positive pressure ventilation (NIPPV) or non-invasive ventilation (NIV).^[3]

From being 'at-risk of to 'requiring and implementing' LTMV	<ul style="list-style-type: none"> - Supply facemask interface - Ensure safe setup of the ventilator equipment in the home setting - Available for troubleshooting equipment problems - Available to provides further caregiver training and support (especially with disease progression) in the areas of ventilator function, back-up battery systems, back-up ventilator function and ability to action skills for emergencies. - Provide overnight oximetry reporting for intermittent monitoring 	Initial visit; then as requested by the acute care CMV team	<ul style="list-style-type: none"> - CCAC - acute care CMV team
From active treatment to end of life care	<ul style="list-style-type: none"> - Potential availability during end-of-life care to ensure that the ventilator is used appropriately and that it does not cause undue stress for the patient. 	Initial visit; then as requested by the acute care CMV team or Palliative Care team	<ul style="list-style-type: none"> - CCAC - acute care CMV team - Palliative Care team

Ontario's [Ventilator Equipment Pool](#) (VEP) is a province-wide resource for mechanical ventilation equipment that is loaned to eligible persons throughout the province. In addition to providing the equipment, the VEP also provides 24-hour telephone technical support seven days per week, equipment service and educational support. They also contract with specific Respiratory Therapists to provide one time in-home instruction on the use of the equipment to new applicants using non-invasive ventilation.

In 2009 Community Care Access Centres in Ontario were given enabling regulation to fund in-home respiratory therapy in much the same way as they provide other in-home therapy services such as OT and PT. However, no additional funds were allocated to the CCACs to support this additional service offering. As a result only a few CCACs have made moves to provide this service.

To prevent hospital admissions and to support people living at home and in the community, access to community respiratory therapy is essential.

Implications for the South West LHIN

Current State – community respiratory therapy

Access to community respiratory care services is currently a significant service gap and as demonstrated by the College of Respiratory Therapists of Ontario report, a community RT model already exists and has been demonstrated to be both clinically and financially effective.

As a result of a funding request put forward to the South West LHIN in December 2012, St. Joseph's Parkwood Hospital received the on-going operating funding the CMV project team requested to develop a RT Outreach program focusing on residents of Participation House Support Services and patients who are discharged from St. Joseph's Parkwood Hospital into the community of London/Middlesex.

ProResp, a local respiratory equipment and service provider, in addition to supplying respiratory equipment and supplies is also providing, at no direct cost, in-home and on-call respiratory therapy services for people living in London and surrounding communities with chronic mechanical ventilation so that they are able to get the level of RT support they need to live in the community. The same kind of service is also being provided by VitalAire in the Owen Sound area.

As part of this project, steps have been taken to develop a process map that outlines the process of moving a person from hospital into the community and supporting them in at home or alternate care setting. It shows how the Community Respiratory Therapist role is integrated into the care process. *See Appendix C for details.*

Proposed Future State – community respiratory therapy

It is proposed that as a future state:

- Community respiratory therapy services be defined as a core service and essential to support on-going living at home and in the community by adults living with chronic mechanical ventilation needs.
- Community respiratory therapy services be readily available to all adults living with chronic mechanical ventilation regardless of where they live within the South West LHIN.
- Community respiratory therapy services be provided in a way that addresses all of the roles and responsibilities outlined in Dr. Leasa’s Chronic Mechanical Ventilation and Community Respiratory Therapy Services table outlined in this document.

More specifically:

Recommendation 5.3.9.1

It is recommended that the South West CCAC expand its services to include community respiratory therapy with a focus on people who are dependent on mechanical ventilation who are living in the community.

The CCAC and its community respiratory services provider should meet with hospital-based RRTs and the RRTs supported by the VEP as part of its implementation planning to clearly define their on-going working relationship and accountabilities and prevent any duplication. It is suggested that the College of Respiratory Therapists of Ontario 2010 report be used as a reference point.

Recommendation 5.3.9.2

The evaluation of Parkwood hospital’s community RT outreach service is to be completed at the end of 2014/15. **It is recommended that the evaluation include in its objectives the role and direction of a community RT outreach service in supporting the community based needs of individuals living with CMV.**

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5.3.10. Community Physiotherapy Services

System Overview

In addition to community respiratory services, community physiotherapy services also play a key role in supporting adults living with chronic mechanical ventilation live at home and in the community.

To quote from the Canadian Respiratory Journal (Vol. 18 No 4 July/August 2011), “Home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline”. Page 200

Adequate airway clearance may be the single most critical therapeutic intervention that prevents acute respiratory failure, undesired intubation and tracheostomy in patients at risk for or using NIV. Airway clearance strategies may help to maintain lung and chest wall compliance through its positive effects on MIC and peak respiratory flows. [*MIC = maximum insufflation capacity*]

The role of community physiotherapy in supporting the prevention and management of airway clearance is outlined in the chart below.

Table 7 Chronic Mechanical Ventilation (CMV) and Community Physiotherapy Services

(Credit to Dr. David Leasa, Respirologist LHSC)

Legend

NIV = Non-Invasive Ventilation

CCAC = Community Care Access Centre

CMV = Chronic Mechanical Ventilation

When needed	Home Services Provided	Frequency	Reporting
Neuromuscular disease + NIV + Reduced cough effectiveness + Respiratory tract infection	<ul style="list-style-type: none"> - Provides temporary home access to a in-exsufflator (using a community resource pool) - Provides teaching for the family/caregivers to ensure safe application in the home 	On-call availability	<ul style="list-style-type: none"> - CCAC - Acute care CMV team

Access to community physiotherapy services is currently being provided through the CCAC. The organization of the delivery of physiotherapy services to support adults living with chronic mechanical ventilation and particular to support the prevention and management of airway clearance can be expected to be undertaken by the Complex Care Coordinators of the CCAC.

There are techniques together with equipment that can be effective to clear airways, one of which is [Breath Stacking](#). This equipment is relatively inexpensive and easy to use. If this type of equipment is not effective then equipment such as an [insufflator-exsufflator](#) may be necessary. This equipment is expensive and is not available through the Ventilator Equipment Pool as it is not an approved piece of equipment under the MOHLTC's Assistive Devices Program²⁰. The need for this resource is occasional for some people and daily and on-going for others, especially when it is related to the progression of their disease.

For occasional users and for those who need it on an emergency basis being able to loan the equipment to individuals for a specific period of time is an option.

For long-term users either a long-term loan or purchase is the most suitable option.

Over many years, many reports and many advocacy efforts the need to identify insufflator-exsufflator equipment as equipment that should be ADP approved and provided through the Ventilator Equipment Pool has been made. To date there has been no success.

Implications for the South West LHIN

Proposed Future State – community physiotherapy services

Recommendation 5.3.10.1

It is recommended that community physiotherapists supported through the CCAC provide in-home prevention and management of airway clearance in collaboration with the other members of the team that is providing on-going support to adults living with chronic mechanical ventilation in the community.

Recommendation 5.3.10.2

It is recommended that a standard screening tool be developed and used by community physiotherapists to assess the need for cough assist equipment and the type of equipment needed.

Recommendation 5.3.10.3

It is recommended that steps be taken to align with clients/patients, families and interest groups such as Muscular Dystrophy Canada to advocate with the government of Ontario to add insufflator-exsufflator equipment to the equipment available through the Assistive Devices Program and the Ventilator Equipment Pool.

Recommendation 5.3.10.4

It is recommended that organizations like MD Canada and other avenues, including ODSP (Ontario Disability Support Program) funding be used to purchase an insufflator-exsufflator if other funding sources are not available and it has been determined that this equipment is necessary on an on-going basis to support the individual's optimal care plan.

Recommendation 5.3.10.5

It is recommended that the South West LHIN be asked to provide the necessary funds to purchase a small number of mechanical insufflator-exsufflators – thereby creating a community resource pool – so the equipment can be loaned out on an as needed basis to people who need it on an emergency or temporary basis.

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²⁰ Excerpt from *Long-term Mechanical Service Inventory Program Final Summary Report*, July 31, 2008, MOHLTC, Priorities for Care and Services, **Review Assistive Devices Program (ADP) policies and processes for ventilator equipment and supplies**. “As well, there is a need for a broader range of equipment (e.g., **cough assist devices**, back up batteries, portable ventilators) to be included on the approved equipment list and more frequent upgrades allowed for individuals with degenerative diseases.”

5.3.11. Primary Health Care

System Overview

The need for primary health care requires special mention because it is an on-going challenge faced by adults living with chronic mechanical ventilation. Having an on-going relationship with a primary care provider, most often a family physician or general practitioner is generally not an issue for someone without a complicated medical or health status – provided finding and being accepted as a patient is not a problem. This has been an issue in the recent past in Ontario but is less so now as primary care reform has been initiated and implemented – and new models of primary health care have been put in place. For this population of patients their primary health care is complicated for a number of reasons – one is the underlying or contributing reason for their dependency on mechanical ventilation; another is the mechanical ventilation itself. For these and other reasons, family physicians are often reluctant to provide care or treatment, not knowing how their intervention might have unintended and negative impacts on the individual. The other complication is that it is medical specialists who generally have the most consistent contact with the individual and understand their particular situation. So, for a primary health care provider to feel comfortable providing primary health care in this context, they might require coaching and support from a specialist. In other words, a shared care model in which there is on-going interaction and communication between the specialist(s) and the primary care provider would be a viable model. Another option would be to have a primary care provider with specialized training and experience work with these individuals, again in partnership with specialists and other health care providers. A model that has been reported as being successful has been CCAC-based nurse practitioners working as the primary liaison with primary care physicians.

Access to primary health care is a critical and foundational part of the healthcare system and adults who are living with chronic mechanical ventilation, like everyone else, need to have access to these services to support their on-going living in the community.

Implications for the South West LHIN

Current State – primary health care

There are organizations such as the South West CCAC who can help individual's access primary health care if they do not already have access to a family physician – [Health Care Connect](#).

The current gap is that in general primary care providers see adults living with chronic mechanical ventilation as a special needs population with complex health care problems that can exceed their level of expertise and comfort.

For family physicians who bill OHIP on a fee-for-service basis the current fee schedule is also a barrier to them providing the level of primary health care needed by adults living with chronic mechanical ventilation.

As a result of primary health care reform there are now capitation models of physician payment which allow physicians more flexibility in how they respond to patient needs. In some models there are incentives to not only provide a group physician practices but to also hire allied health resources to expand the capacity and scope of what can be offered. These new models are in addition to Community Health Centres which are community board-led primary health care organizations where physicians are salaried and allied health care professionals are also employees.

Proposed Future State – primary health care

Solutions to addressing the need primary health care needs of adults living with chronic mechanical ventilation can vary but they lay in the direction of shared care and building a relationship with primary care providers who have ready access to the support they need to fulfill their primary health care role. By having this in place they are able to grow, learn and increase their comfort level when serving this population. As a practical example, the Children's Hospital at LHSC is encouraging parents to take their child to their family physician for vaccinations; something that does not have complications associated with it but allows an opportunity for familiarity to develop.

Other options include developing relationships with Family Health Teams (FHTs) – these teams have a multidisciplinary team of health care providers. The physicians affiliated with FHTs are funded through a Family Health Organization (FHO) physician payment model and as such they are paid through a capitation and incentive model.

In general, using the primary care provider or physician that is local, known and respected by the family and patient is the most sustainable model. The care provided can be affiliated with a variety of primary care models but this is less important than their availability, accessibility and ability to provide core primary health care services. Partnering with the 'core' health care services that specialize with serving this population is a key success factor and essential for clinical direction, support and mentoring.

Access to primary health care services should be defined as a core service and essential to support on-going living at home and in the community by adults living with chronic mechanical ventilation needs.

Recommendation 5.3.11.1

It is recommended that steps be taken to engage with each patient's primary care physician and keep them informed about the health care being provided in the hospital, in the community and at home, and that the South West CCAC Complex Care Coordinator – nurse practitioner - be asked to take a lead role in doing this.

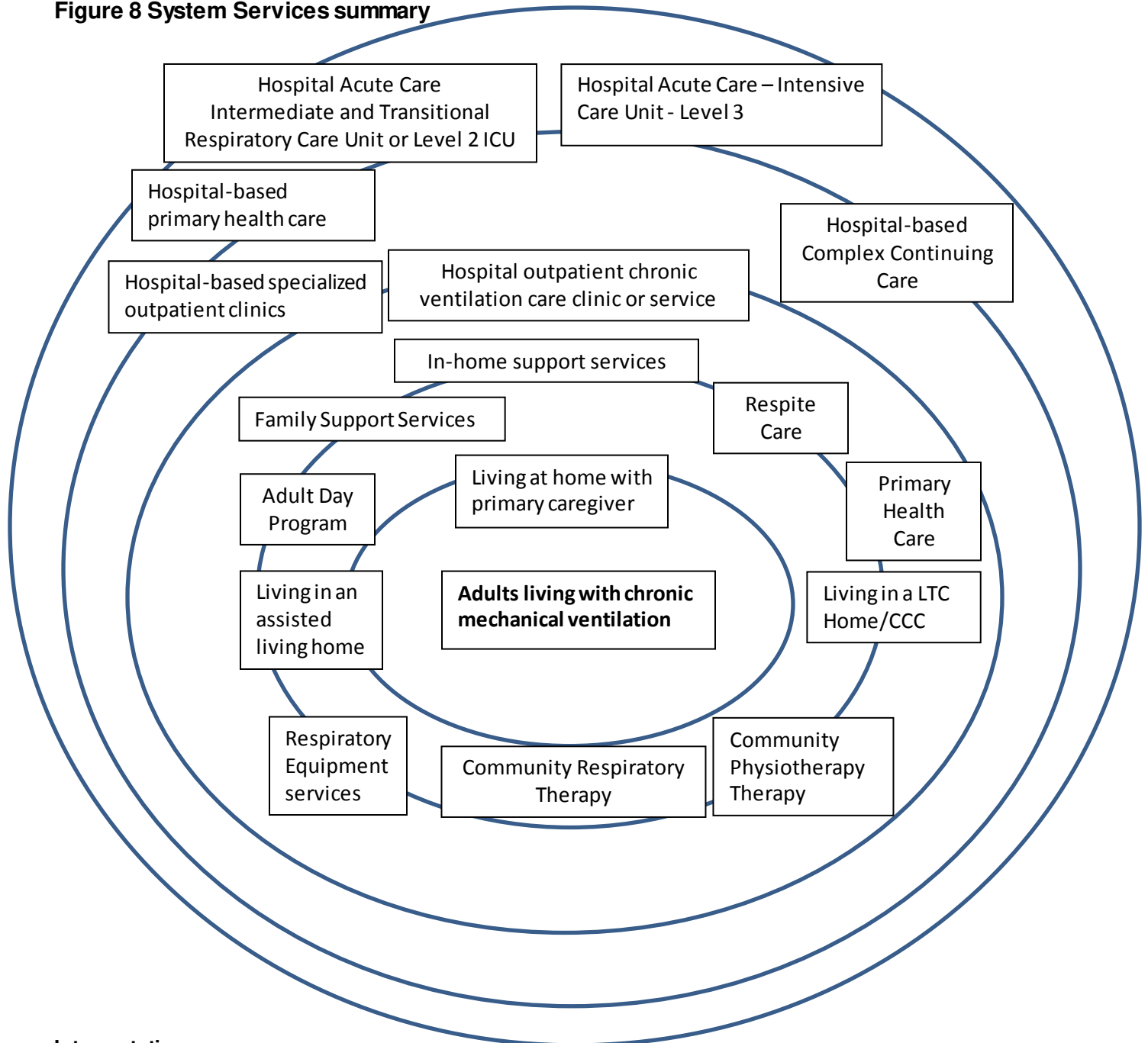
Recommendation 5.3.11.2

It is recommended that the health care services that support adults living with chronic mechanical ventilation to live in the community, work with the client's primary care physician (or primary health care team) to define on-going roles and relationships and that the South West CCAC Complex Care Coordinator be asked to take a lead role in doing this.

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5.4. System Services Summary

Figure 8 System Services summary



Interpretation

This diagram is intended to: 1) put the person living with chronic mechanical ventilation at the centre 2) in concentric circles, show those people, settings and services most directly and consistently involved in the person's life and with their primary caregivers. Hospital-based services occupy the outer two rings. Outpatient services serve an on-going role in the person's life in the community and are therefore closer to the person's life than hospital inpatient services. Inpatient services are designed to be time limited and to be able to move the person back into the community. The most highly specialized medical service is the hospital acute care intensive or respiratory care unit. It has highly skilled medical and allied health care expertise to intervene when people are critically ill and in this situation they initiate both invasive and non-invasive ventilation. When this immediate intervention results in the person having an on-going dependency (i.e. chronic need) for respiratory ventilation then they are able to work with the person until they can transition to another setting.

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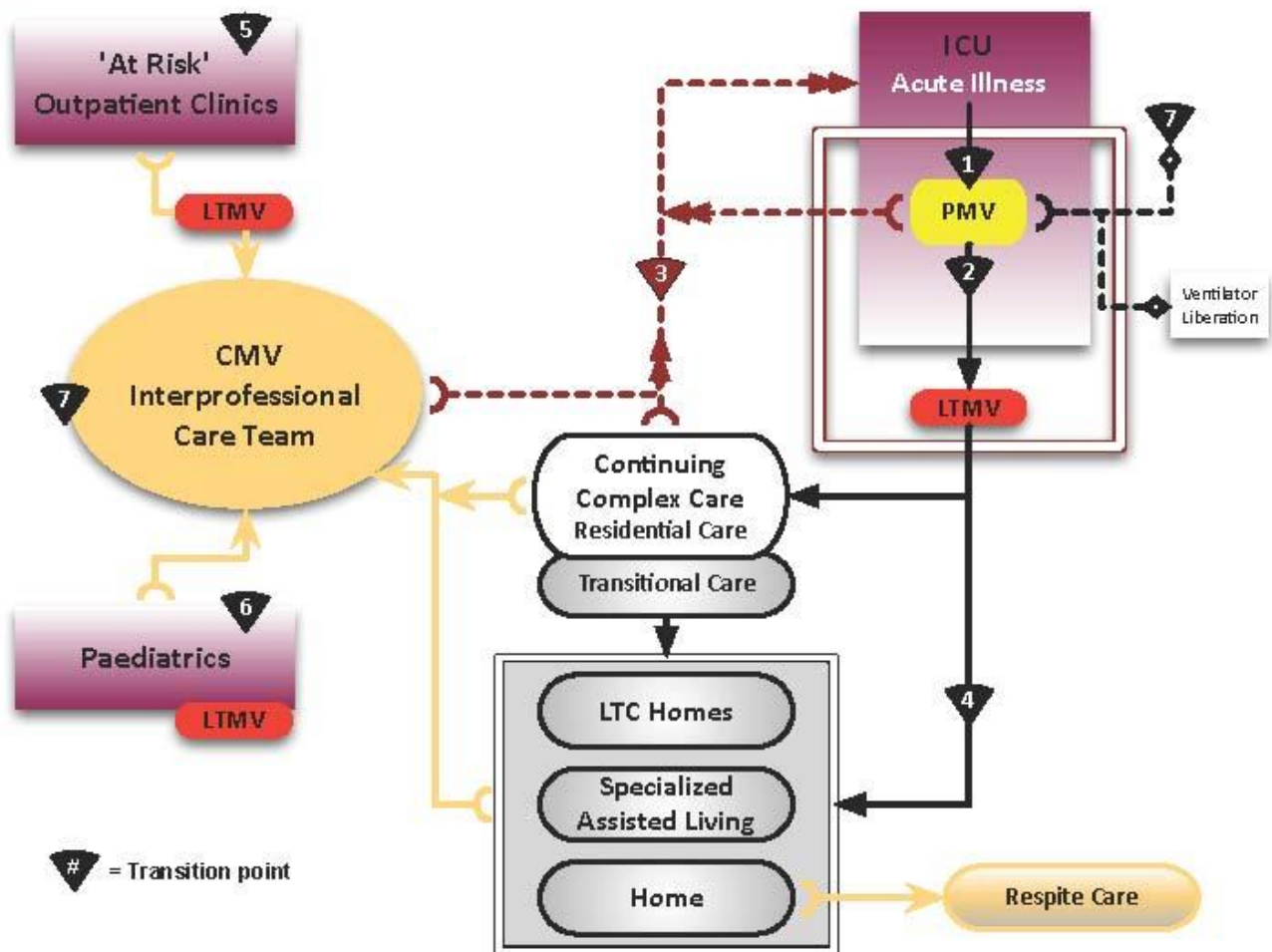
6. Movement and Transitions

System Overview







In addition to being able to describe and define the different settings and services that make up the system of health and supportive care services for adults with chronic mechanical ventilation it is important to be able to describe how they connect and how people move through and interact with the system. The following flow chart describes this movement from a health care perspective. Numbers used throughout the chart note key transition points.

Figure 9 System movement and Transitions

Source: Dr. David Leasa, London Health Sciences Centre



Legend

CMV = Chronic Mechanical Ventilation	1 Transition from ventilation in the acute phase of illness to PMV
LTMV = Long-Term Mechanical Ventilation	2 Transition from PMV to LTMV
PMV = Prolonged Mechanical Ventilation	3 Transition from PMV or LTMV to acute critical care ventilation (reverse transition)
LTC = Long-Term Care	4 Transition from institutional care to care within community (home/assisted living)
 = Transitional Respiratory Care Unit	5 Transition from 'at-risk of' to 'requiring' LTMV
 = Community Care	6 Transition from pediatric to adult services
 = Scheduled followup care	7 Transition from active treatment to end of life care for PMV or LTMV
 = Ventilator discontinuation	
 = Care venue transition	
 = Acute care transition	

From a system of care perspective it is the transitions in care that define how well the system is functioning “as a system”. The timing and appropriateness of the transitions, how well they are planned and executed are hallmarks of how well the system is working as well as the quality of relationships with clients/patients and their families, among the participating service providers and organizations.

The nature of the conditions that adults living with CMV have means that they have an on-going relationship and involvement with health and supportive care services, although the frequency and intensity of this involvement can be highly variable both between individuals and on the part of a specific person. Nevertheless, movement between services, involvement with multiple services at the same time and transitions from one set or type of service to another is a common pattern as Figure 5 illustrates.

In addition to the transitions and movements outlined above there are two transitions that are so significant that they warrant special attention. One of these is the transition from pediatric to adult services; the other is the transition to palliative and end of life care.

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6.1. Transition from pediatric to adult services

System Overview

The transition from pediatric to adult services is a critical one in the lives of children/adolescents and their families. One of the most important things to acknowledge is the transition process itself. Parents and families develop an intimate relationship with their care providers as they jointly work to manage and address the complex health needs of their child/adolescent. Parents develop an intuitive understanding of their child’s needs that are communicated and respected by care providers. Losing this relationship can be a significant loss filled with uncertainty and fear.

There is a significant difference between the services offered to children and what is available to adults – in many ways they are different worlds - and unfortunately the transition can be experienced as a significant loss rather than as simply a transition. For example, as children a primary contact for primary health care purposes is a pediatrician.

As they become adults, pediatricians are no longer in a position to care for them; and yet, in most cases a family physician has not been involved – so how can the primary care needs of these individuals, as adults, be addressed?

Transition from pediatric to adult services

The transition from pediatric to adult services should be acknowledged as a significant milestone in the life of a person living with chronic mechanical ventilation

Recommendation 6.1.1

It is recommended that and that specific structures, processes and supports be developed to support individuals living with chronic mechanical ventilation needs through the transition from pediatric to adult services.

Implications for the South West LHIN

Current State

It is because of this reality that the Children's Hospital at LHSC has recently implemented an outpatient clinic specifically to support adolescents and their families through the transitional process. The intent is to begin this process several years before the transition occurs (ideally at age 14) – knowing that the transition occurs at different times depending on what sets of services are involved. One focus of their attention is to document their situation so parents do not need to repeat their story with each new adult health care provider – they can use the document as a communications tool with others. Another focus is to ensure that connections with adult medical specialists are made so that continuity of care can be realized. This connecting or system navigation role includes bringing different hospital-based pediatric health services together with related adult hospital-based services together to plan for the transition from pediatric to adult services. There is currently no equivalent role in the adult system. If this role was in place, the coordination and transition process would have an accountable “point person” from both sides that would partner to manage and facilitate the transition.

The Children's Hospital at LHSC is addressing this issue, in part by encouraging families to include their family physician in the primary health care of their child, in collaboration with their pediatrician. However, when the needs of the child/adolescent are very complex the family physician may not feel that he/she is in a position to provide primary health care. With proper supports this concern can be addressed. The primary health care section of this report has made a number of recommendations to address this service gap.

Another significant issue is respite care which is a lifeline for families being able to sustain their on-going primary caregiving role. Respite care is available for children through Kids Country Club and of course school-based day programs with [CCAC](#) support. Neither of these respite/day programs is available once a young adult turns 21 years of age – and yet the needs of the young adult and family have not changed. Importantly, while a child/adolescence has the right and is entitled to attend a school day program, there is no right or entitlement associated with adult day program services. Until very recently there was no assigned or designated community-based day program or respite care specifically designed to include adults with chronic mechanical ventilation needs.

In March 2013 the South West LHIN Board approved a proposal to allow Participation House Support Services to provide, “overnight respite services including provision of complex care required by this population [medically fragile young adults 18+] including administering and monitoring oxygen, taking and monitoring vitals, suctioning, providing chest physiotherapy and administering medications and formulas via feeding tubes”. This funding will allow overnight respite care for two individuals seven days a week with the goal to accommodate four different individuals per week. In addition and at the same time, Participation House was awarded funds to provide day program services for two individuals five days a week, with the goal to accommodate six different individuals per week.

The reasons given for supporting these two proposals speak directly to the issues faced by families as their children/adolescents become adults. To quote from the March 2013 South West LHIN Board agenda package:

It is recommended that an overnight respite service be created and day program spaces be increased for medically fragile young adults (18+). These enhancements would assist to enable families to continue to support their medically fragile older children at home by providing respite and avoiding crises situations where hospitals are the only alternatives.

Medically fragile children have access to a multitude of resources until the age of 18 or until they leave high school. At the time of transition to adulthood, these medically fragile young adults and their families lose access to a variety of services including children's overnight respite, in home respite, augmentative communication resources, and paediatric specialists to name a few. Families desire to continue to support

their medically fragile adult children at home but have limited access to respite services and their children have limited access to meaningful activities. In order to help to support families to continue to care for their medically fragile adult children, supports are required to prevent crises situations.

This investment is a very positive development as it provides an opportunity for young adults and their families, including those who are living with chronic mechanical ventilation needs, to receive two key support services – overnight respite care and day programming that had previously not been available. It provides an example of how community supportive care services need to expand to support living at home.

From a financial perspective, the source of funds that support children and families changes when they turn 18 years of age. Fortunately, while child-based funding ends, people can apply for the Ontario Disability Support Program ([ODSP](#)) six months before they turn 18 and this opens up a new source of on-going financial support.

From a future state and system modeling perspective there are two key elements associated with the transition from pediatric to adult services that need to be addressed. One is to support the work that the Children's Hospital has undertaken by providing parents and their children with the tools to proactively prepare them for the transition to adult services. The second is to ensure, as much as is possible, that the supports and services made available to families – while they might not be the same, are sufficient to enable a family to support their loved one as long as it is appropriate and they are willing and able to do so, knowing that there might be a time when this might not be possible or in the best interests of their child. Primary among these is respite care and day programs together with alternate living settings.

Current State Summary

The current initiative that has been undertaken by the Children's Hospital will go a long way toward addressing process issues as they apply to adolescents and young adults transitioning from pediatric to adult services.

There is currently no formal mechanism to bring service providers together who will be involved in the “handoff” between pediatric and adult services – having a mechanism in place is critical given the significance of the transition for both the client/patient and their families.

Recent steps by the South West LHIN have acknowledged the need for both day programs and overnight respite care for this population.

There are both service gaps and differences when an adolescent or young adult transitions to adult services. The service gaps identified in this paper – once addressed – will assist in making this transition a smooth one. Meanwhile, health and supportive care organizations need to work together to address gaps as best they can and work collaboratively in the best interests of the adolescent or young adult as they transition to adult services.

Proposed Future State - transition from pediatric to adult services

Recommendation 6.1.2

It is recommended that the transitional care clinic of the Children's Hospital at LHSC continue to be the primary point of contact for identifying adult service needs and coordinating the transition of care from a pediatric perspective

Recommendation 6.1.3

It is recommended that a primary service coordination or system navigation role be identified from among adult services to serve as a liaison with the Children's Hospital and with adult services on a system-wide basis. One option is to designate the recently established CCAC Complex Care Coordinator role to include this responsibility.

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6.2. Transition to palliative and end of life care

System Overview

People who need support and assistance to live with chronic mechanical ventilation are often compromised in terms of their overall health status and life expectancy. At the same time, life expectancy can vary depending on the underlying condition and circumstances that have led them to need this kind of support. And, as with any person's life, individual circumstances are unique and outcomes are difficult to predict.

At the same time, there is a responsibility and accountability on the part of the health care system to provide vulnerable persons, especially those who live with a dependency on mechanical ventilation and their family and loved ones, with the opportunity to:

- Talk to a palliative care professional who can:
 - Talk to them about palliative and end of life care
 - Support the patient to clearly express their wishes
 - Ensure that these wishes are documented and periodically reviewed and updated as needed

In addition, from a systems perspective, it's important the document is known and available to everyone who is part of the person's circle of care and that in whatever way is secure, private and yet practical, there is ready access to this information.

It's also important that the agreed upon document is transferrable. That is, once the person has gone through the difficult process of defining their wishes and having them documented, it is incumbent that the system of services that are working to support the person accepts and references the same document as the person encounters different services or organizations.

There are already standardized forms available for the purpose of documentation. These should be reviewed so that a standard form can be accepted and used by all services.

There are, of course, people who have already made their wishes known and have had them documented. In these situations their current wishes simply need to be made accessible to those who need access to this information.

Finally, rather than leaving it to chance, the offer of palliative and end of life support should be made available before it needs to be acted on. One option is to include it as a consistent part of the education and orientation around a person's transition to using non-invasive ventilation or invasive ventilation as the case may be. Sensitivity concerning the timing and appropriateness of this conversation is important, but equally important is having an understanding of the person's wishes in this area and connecting them with a palliative care professional that has the experience and expertise to guide them through this conversation. Not having the conversation or not offering one as a routine matter should not be an option.

The second phase of this process is the organization of services to deliver on the wishes expressed by the person when they need to be implemented. As noted at the outset of this section, the circumstances that will trigger the transition to palliative and end of life care are widely variable and individual. Nevertheless, the basic principle is that it needs to be a collaborative approach that respects the wishes of the individual and does so in a way that applies best palliative care practices.

The transition to palliative and end of life care should be acknowledged as a significant milestone in the life of a person living with chronic mechanical ventilation

Recommendation 6.2.1

It is recommended that that specific processes and supports be developed to proactively plan with and support all individuals as they move into palliative and end of life care.

Implications for the South West LHIN

Current State

There are a number of services that focus attention on palliative and end of life care in the South West LHIN area. In addition to palliative care services offered in hospitals, there are a number of community services that support palliative and end of life care. A primary resource is the South West Hospice Palliative Care Network. To quote from their web site:

The South West Hospice Palliative Care Network is an alliance of community agencies, hospitals, long-term care homes, and other stakeholders who are all committed to continuously improving hospice palliative care services.

Leveraging the Government of Ontario's Declaration of Partnership and Commitment to Action; Advancing High Quality Palliative Care in Ontario and through Partnerships with other End of Life Care Networks within Ontario: Hospice Palliative Care Ontario, Canadian Hospice Palliative Care Association, Virtual Hospice, and

others, the South West Hospice Palliative Care Network strives to advance exceptional hospice palliative care in our communities. Its mission is to improve the hospice palliative care system for everyone through integration, advocacy, education, best practice promotion, and system evaluation.

The Network is one of several that formed across Ontario as part of the provincial government's End-of-Life Care Strategy in 2004. The original mandates of the Networks were as follows:

- Broad system design
- Coordination and integration of services at the system level
- Promotion of service innovations
- Monitoring and assessment of community needs

From a hospital perspective many hospitals offer inpatient [palliative care](#). They provide a full range of services for people who are in the final stages of their illnesses, as well as their families and/or caregivers. Services may include medical care, pain and symptom management, consultation, specialty units, volunteer visiting, counselling and bereavement services.

[Community-based hospice services](#) exist in many communities across the South West LHIN. In most cases this involves trained volunteers providing support and respite to individuals and their families who are facing life-threatening or life-altering conditions, as well as those who have lost a loved one. These services offer support in the home as well as through centre-based programs.

There are also a small number of residential hospice services in the South West LHIN. The South West LHIN has recently approved operating funds for a 10 bed residential hospice in the City of London and earlier this year the South West LHIN approved the development of six residential hospice beds in Owen Sound to serve Grey and Bruce counties in addition to resources to support an outreach consultation service. A 10 bed hospice business plan is under development (this would add four beds to the ones currently approved).

There are no residential hospice beds in Huron or Perth Counties although as already noted, most communities in the South West LHIN provide hospice outreach services through a combination of volunteers and paid staff.

A third party review of palliative care services in the City of London has been completed and a number of recommended changes have been proposed.

As noted above, adults living with CMV face special challenges when it comes to palliative and end of life care. There is no doubt that in a number of cases the disease or condition with which they are living compromises their life expectancy. They are vulnerable to infections and therefore through the nature of their condition and the circumstances under which they live decisions about how they wish others to respond if or when their health deteriorates is important. At the present time a protocol is not in place to ensure that, on a consistent basis, adults living with chronic mechanical ventilation have the opportunity to talk about their wishes for palliative and end of life care and that a plan of care is developed with them. There is also no process or documentation in place that can be used on a system-wide basis to ensure that the agreed upon plan of care is shared, known, accepted and used by all health service providers.

Proposed Future State - transition to palliative and end of life care

Recommendation 6.2.2

It is recommended that steps be taken in collaboration with palliative care experts to:

- **Develop a consistent process to engage each newly diagnosed person with chronic mechanical ventilation in a conversation in which they have the opportunity to express their palliative and end of life care wishes and co-create their plan of care – one that is documented and can be used on a system-wide basis.**
- **Initiate, plan and implement a pilot project focused on newly diagnosed persons with ALS.**

Recommendation 6.2.3

It is recommended that a primary contact for palliative care coordination for each person is designated and that when appropriate, all service providers' work together to implement the plan of care as agreed, in collaboration with the family and the client/patient.

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6.3. Service Coordination and Planning

System Overview

Service coordination and planning involves providing the health and supportive care needs of the patient/client in a range of circumstances. One aspect of care coordination is the identification of the patient/client's designated place of residence, which is where the individual is receiving their day-to-day supportive care and serves as their home.

Care planning for adults living with chronic mechanical ventilation needs to incorporate both health and supportive care planning to provide a comprehensive, integrated and individualized care plan and delivery.

Regardless of the environment an individual with chronic mechanical ventilation is living, multiple service providers and organizations are likely to be involved to ensure that care is integrated and services are coordinated. The most commonly occurring types of service coordination are listed below.

- Coordination of care provided within a given organization.
- Coordination of services provided by a number of organizations or providers.
- Coordination of transitions

In each case it is important that there is a designated person who serves as the 'quarterback' or navigator – someone who is responsible for ensuring that care is being coordinated in an effective manner.

Coordination of care provided within a given organization

There needs to be someone (a "service navigator") within the organization who is responsible for coordinating the delivery of care that each patient/client receives from that service, agency or organization. The goal is to ensure that the care provided within each service is coordinated so they are able to meet the needs of patient/clients while they are in their care. This person would be involved in coordinating the transition of the patient/client to another service provided by the same organization, and may also be involved in coordinating the transition of the patient/client to another organization, facility or home. It is assumed that this would be organized following the normal "navigation" practices of each service.

Coordination of Transitions

As noted earlier, transitions are a key dynamic in the lives of adults living with chronic mechanical ventilation and need to be both planned and coordinated. Three different types of transitions are profiles below: scheduled temporary, unscheduled temporary, and permanent.

Scheduled Temporary Transitions:

Responsibility for initiating, planning and coordinating temporary scheduled transitions, including transportation etc., should rest with the home, facility, or organization that serves as the patient/client's designated place of residence. The goal is to have one person or "number to call" within an organization to arrange a scheduled service and to coordinate any arrangements needed to support the temporary transition.

Unscheduled Temporary Transitions:

As above, responsibility for initiating unscheduled transitions, including transportation etc., would rest with the home, facility, or organization that serves as the patient/client's designated place of residence. The goal is to have pre-defined procedures and protocols in place that are activated under pre-defined circumstances. These procedures and protocols (sometimes referred to as Standard Operating Procedures or SOPs) need to be negotiated and agreed to, in advance by the participating organizations. A good example is the development of a SOP that would define the conditions under which a client living with chronic mechanical ventilation in the community would be transferred to the ICU (by activating 9-1-1).

Permanent Transitions:

There needs to be a defined planning process involving contacts from the affected organizations to plan and then coordinate a permanent transition of a patient/client's care team and/or designated place of residence.

Proposed Future State – service coordination and planning

Case Conferencing and Care Planning

Health and supportive care sectors have well established, but differing practices for care planning. It is expected that health care providers will follow established case conferencing and health care planning involving the patient/client, primary care givers and supportive care providers as appropriate. The expectation is that supportive care providers will follow established individualized care planning practices followed in the supportive care sector with the involvement of health care contacts as appropriate.

Complex transition situations involving multiple providers and transitions require a lot of pre-implementation planning and training so it is expected that comprehensive case conferences and care planning sessions will be held to ensure everyone involved with and/or responsible participates in the decision-making and agrees to how the process will be managed and undertaken. In each case someone will be designated as the 'quarterback' to coordinate the process. This same process should be used to support a person through life transitions and care planning such as end-of-life care and support.

Coordination of services provided by a number of organizations or providers

There needs to be someone (a "system navigator") who is responsible for overseeing the coordination of care provided by a number of organizations and services. The complexity of this role will depend on the number of patients/clients and the number of distinct services that are involved in caring for adults living with chronic mechanical ventilation. The goal is to ensure seamless and coordinated delivery of the range of services provided to each adult living with chronic mechanical ventilation. This person would be involved in the coordination of temporary or permanent transitions involving other organizations, facilities or homes.

It is proposed that the service providers who are assuming primary responsibility for providing health or supportive care also assume responsibility for coordinating services with others. This means that while a person is in hospital, a hospital staff person would assume service coordination responsibility. If a person is living in an assisted living home a staff member at that home would assume this role. For people who are living at home, care coordination could be assumed by a family member or by the Community Care Access Centre Care Coordinator.

The coordination role as described has a primary mandate to be an effective communicator and collaborator – bringing the necessary people together to make decisions and develop specific action plans.

Recommendation 6.3.1

It is recommended that each organization that is involved in the delivery of services to adults living with chronic mechanical ventilation designate an existing staff member with the responsibility to be the key service coordination contact for their organization

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7. System Leadership and Accountability

The day-to-day coordination and provision of health and supportive care services, among the participating organizations and services providers, is addressed in section 6.3 of this document. The provision of seamless care, particularly when it involves transitions or coordination of services between two or more organizations or service providers is one of the fundamental guiding principles of the proposed systems model, and will require the active involvement of the adults living with chronic mechanical ventilation, their families, and primary care providers.

Establishing and sustaining a successful regional care system for adults living with chronic mechanical ventilation will require the development of a cost-effective systems management infrastructure that has two fundamental components, namely:

- The infrastructure needed within each participating organizations to ensure the provision of quality, timely and seamless services to adults living with chronic mechanical ventilation and to fulfill its associated administrative, coordination and leadership roles.
- The infrastructure needed to effectively administer, lead, coordinate, report on the collective operation and performance of the regional system for providing health and supportive care to adults living with chronic mechanical ventilation. This includes the necessary governance infrastructure to define the relationships and mutual accountabilities among the participating organizations.

The purpose of this section is to describe those parts of the systems model that are associated with providing region-

wide system coordination and leadership needed to establish and sustain the coordinated and seamless deliver of care to adults living with chronic mechanical ventilation.

7.1. System Coordination and Leadership

System Coordination

System coordination addresses the components and functions required to coordinate, evolve and sustain an integrated system of health and supportive care services for adults living with chronic mechanical ventilation across the South West LHIN. The focus is on how the participating organizations align their services and work together so that their staff can provide effective and seamless service delivery and coordination.

A fundamental principle put forward at the outset of this project was that the organizations involved as project sponsors support a systems model of service delivery to this population. Implementing a systems model would not only put the needs of the patient/client at the centre but would also redefine how the organizations and staff make decisions and work together. Fundamental to the systems model is the collective commitment to coordinate care across organizational boundaries with the associated joint responsibility and accountability for the quality of care provided and the overall impact on regional health and supportive care services across the South West LHIN.

System coordination at its core means that the participating organizations have collectively:

- Defined the range of services required, and who is responsible for the delivery of each service including geographic coverage where applicable;
- Established health and support care protocols and practices that are appropriate especially in situations where the care is being provided by people who are not specialists;
- Established policies, procedures, and agreements that promote, support and reinforce shared decision-making and shared service management – and service coordination;
- Established and implemented service coordination and planning mechanisms;
- Put mechanisms in place to handle the introduction of new patients/clients into the system including the resolution of any operational, care or funding issues; and
- Established how to effectively lead, govern, and hold the integrated system of care for adults living with chronic mechanical ventilation accountable.

The interdependencies among the services that have been described in this paper are significant. No one organization or service can change the nature of the services provide or it working relations, within the scope of the Systems Model, without having a significant impact on others. It is the need for seamless alignment and collective accountability that needs to be reflected in policies, procedures, and agreements.

Significant work to develop the required system coordination mechanisms will be required in the next phase of this project.

System Leadership

System leadership involves those who have formal operational, management, and governance responsibilities for the programs, services, and infrastructures necessary to provide coordinated and seamless health and supportive care to adults living with chronic mechanical ventilation across the South West LHIN. System leadership includes leaders within each participating organization that have designated leadership roles covering their organization's contributions to the regional system, as well as designated regional system leadership and administrative roles needed to effectively lead and administer the overall operation of the regional system of care for adults living with chronic mechanical ventilation.

The proposed regional system leadership structure includes the **Regional Oversight Committee** consisting of designated leaders representing each participating organizations. The purpose of this Committee is to provide regional system planning, system coordination, assessment of regional system's performance, and provide communications and other functions on behalf of the regional system caring for adults living with chronic mechanical ventilation within the South West LHIN. The success of this Committee will depend on the mutual commitment of its members to come together and making decisions that serve the interests of this population ensure that everyone is working towards a common purpose, share a common vision and fully recognize the implications of being parts of a comprehensive and cohesive system of services. In sum it means sharing system-wide accountability.

In addition to having representatives from the organizations that are providing health and supportive care to this population, it is proposed that the Regional Oversight Committee include at least three representatives who are adults living with chronic mechanical ventilation and/or family members.

From a system change perspective, the commitment and motivation to work in close collaboration with others cannot

just be altruistic; it needs to deliver returns for the investment in time and resources required to make it successful.

It is anticipated that the scope of the Regional Oversight Committee will include the following mandate:

To ensure:

- From a patient /client care perspective that the regional system is truly patient and family-centred.
- A return on investment in terms of improved quality and outcomes for clients/patients, and to the participating organizations and providers.
- Sustainability of the regional system in terms of funding and regional care capacity to accommodate the growing number of adults living with chronic mechanical ventilation.
- The regional system is efficient and effective, takes waste out of the system, prevents duplication, improves productivity and is innovative – in other words improve system performance.
- From a service provider perspective that the regional system is coordinated, applies best practices and delivers high quality care and outcomes.
- That the regional system functions on the basis of a shared commitment to all participating organizations and care providers working together for the good of adults living with chronic mechanical ventilation, continually improving the quality and cost-effectiveness of the collective services; shared accountability for on-going collaboration and a commitment to formalizing, supporting and sustaining the proposed 'system'.

Proposed Future State - Accountability

Mechanisms for shared accountability for the overall system operation and performance and well as processes for participating organizations to hold each other accountable for fulfilling their roles and responsibilities need to be developed and applied. The need for transparent accountability is vital given the high degree of interdependence that links services together to provide a coherent and seamless system of health and supportive care. The key will be the ability of participating organizations to work effectively together and adapt to accommodate unexpected situations putting the best interests of patients/clients first.

Recommendation 7.1.1

It is recommended that the organizations that individually and collectively share responsibility for the delivery of services to adults living with chronic mechanical ventilation formally agree to be held accountable for overall system design, planning, development and performance improvement.

To achieve this result all participating organizations commit themselves to establish:

- the leadership, clinical and administrative support, and standard operating procedures necessary to lead and coordinate health and supportive care services, each organization provides to adults living with chronic mechanical ventilation;
- the formal accountability agreements defining the associated governance and mechanisms for shared management and accountability among the partner organizations, and the infrastructure needed to ensure the effective system coordination including relations with patient/clients and primary caregivers;
- the recommended Services Coordination and Regional System Oversight Committees and the necessary Regional leadership and infrastructure needed to provide strategic direction, priorities, set and implement common standards and processes, define system performance measures and goals, and address other system-related matters; and
- Organize an annual review and planning forum with the outcomes of the review and planning session provided to interested parties, and be used to guide the operation and initiatives to improve the Regional System's performance.

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7.2. System Performance Assessment

Key to the success of creating a regional system to care for adults living with chronic mechanical ventilation will be the ability to measure system performance and therefore having the information and tools to assess change and address issues. This is not only an essential tool for system leaders but for everyone.

A workshop with South West LHIN staff was held in early January to develop an accountability framework.

In terms of alignment with the 2013-16 Integrated Health Services Plan (IHSP) of the South West LHIN this initiative is aligned as follows:

- Primary Strategic Direction: Enhancing transitions and coordination of care
- Possible second direction: Increasing the value of our healthcare system for the people we serve

At the workshop four major system indicators were put forward and discussed.

1. Reduction in ALC (Alternate Level of Care) days associated with LTV (Long Term Ventilation)

This refers to people who continue to be inpatients in an acute care hospital when they no longer need that level of care. As a system one objective that has already been addressed is to use and develop options and alternatives so that people can transition out of acute care when they need to.

- As a corollary to acute ALC is tracking the wait list for alternate services – in the community or hospital sector (complex care) as they are inter-related.

2. Reduction in the number of inappropriate transitions of care

This can refer to transitions (people moving from one setting or service to another) at any point in the system - so while the first indicator refers to transitions not taking place when they should, this refers to transitions taking place that would not be needed if the system or resources were in place to either prevent the admission or support a more appropriate transition. For example, while an acute care hospital admission might be appropriate under some circumstances, admitting a person to hospital because a community setting was not available is an example of a transition that might not be appropriate. An appropriate or inappropriate transition will need to be operationally defined.

Examples of indicators include:

- Number of crisis that resulted in acute care hospital admission
- Number of times individuals are sustained in the community through an acute illness or episode
- Number of times case conferences were held to plan, execute and reflect on the transition

3. Provider/patient satisfaction

While subjective, knowing (by asking) how well the system is functioning and meeting the needs of particular individuals and families is fundamental. There are three key dimensions to this matter. One involves the way in which people living with chronic mechanical ventilation and their families are involved and participate in the 'circle of care'. The second has to do with how well they see the services working together and coordinating care and the third involves outcomes – how do they see or interpret the results of the services provided.

- **Patient/care-giver satisfaction with respite services** – this is a particular component of the system but so fundamental to supporting families and primary caregivers that it is seen as being important enough to warrant special attention.
- **Satisfaction with transitions of care** – service providers, families and individuals living with chronic mechanical ventilation need to be asked about the experience and offer suggestions for improvement.

4. The capacity of the system to meet current and future needs

One of the components of this initiative, in addition to defining the desired future state, is to identify current gaps and to anticipate future demands so that plans can be made and actions taken to address the future as it evolves. One way of doing this is to understand how people come into the system and how their needs change over time. A process for identifying persons "at risk" for chronic mechanical ventilation in the community is proposed – as is a process for identifying persons living with non-invasive ventilation and how their needs might change to trigger a need to use invasive ventilation. Fortunately a database already exists to monitor individuals who are 'at risk' and who are part of the system.

- From an outcome perspective it is important to document where capacity has been developed and its impact on the system on an on-going basis.

Recommendation 7.2.1

It is recommended that the operational metrics outlined in this paper be used as the basis for monitoring and assessing system performance on an on-going basis. This includes:

- reduction in ALC (Alternate Level of Care) days associated with LTV (Long Term Ventilation);
- reduction in the number of inappropriate transitions of care;
- provider/patient satisfaction, patient experience, and quality of life;
- system capacity to meet current and future needs

- operational metrics that categorize and document experiences of adults living with chronic mechanical ventilation when transitioning between stages in their health and supportive care services including 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;
- population health metrics to assess the overall regional system's ability to provide coordinated and seamless care and provide a cost-effective system for delivering health and supportive care to the population of adults living with chronic mechanical ventilation.

See Appendix D for details.

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8. A Commitment to Excellence and Partnerships

Throughout the description of services that make up the proposed system references have been made to using and teaching standards-based clinical care. Reference was also made to the role of technology and how advancements in this field are continually changing the options and opportunities available. While not explicitly stated, the underlying theme is one of a commitment to excellence. In simple terms excellence means doing the best one can with the tools and resources available, together with one's creativity, passion, skill and determination. In this context excellence means harnessing the resources and talent that everyone has to contribute. That is both the challenge and opportunity that lies ahead.

As a system of services no one person, service, agency or organization can serve the health and supportive care needs of this population by working in isolation. Creating, sustaining and growing relationships through partnerships are the lifeblood that will create, foster and strengthen service and system coordination, planning and leadership.

9. Next Steps

This discussion paper represents the major deliverable for Phase 1 of the project.

Phase 1 deliverables

- A clearly defined and agreed upon vision
- A model of the continuum of health and supportive care
- A model of the operational processes needed to support system-wide quality of services, transitions, continuity and coordination of health and supportive care

At the end of Phase 1 it is important that this paper be widely circulated for information and comments. In particular it's important to get expressions of support before moving onto implementation planning. It's also an opportunity to get input on which recommendations are seen as most critical – those to be planned and implemented first.

Phase 2 deliverable

- A resource needs analysis and plan to implement the continuum of care and operational model as defined, including the infrastructure, resources and funding needed to address gaps and operate the system.

Phase 3 deliverables

- Implementation, on-going operations and sustainability including the structure, processes and resources to support on-going evaluation, process improvements and planning for the future

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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 hypoventilation 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 (through 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.

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VAI = Ventilator Assisted Individuals
HMV = Home Mechanical Ventilation

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.

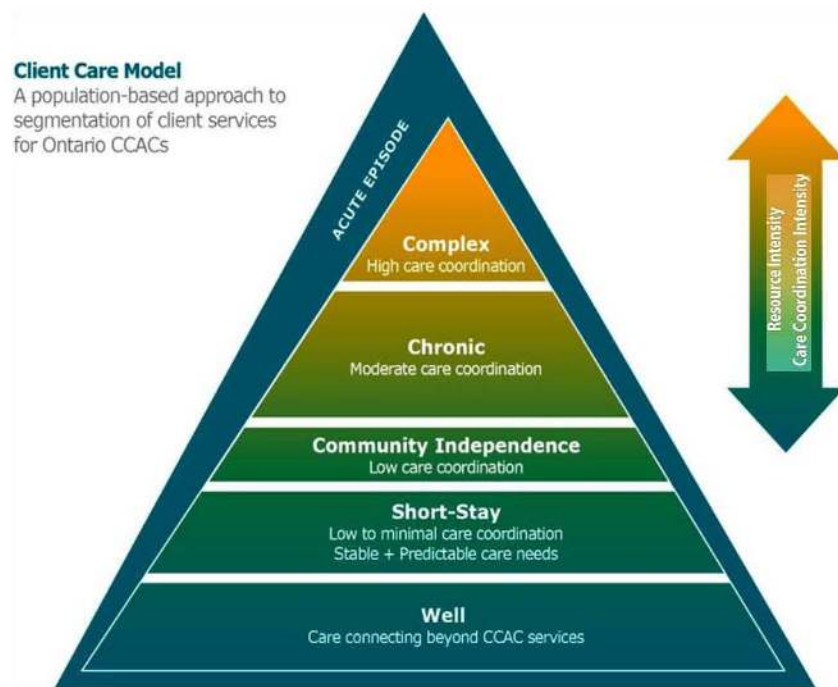
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Client Care Model Pictorial Representation

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 Pictorial Representation



Client Care Model – Population and Sub-Population Definitions	
Complex	1 or more health/chronic conditions with complicating factors; Direct care needs are unstable & unpredictable; The individual or support network is not self-reliant with high risks in more than 1 area; RAI score 17+; High/intensive care coordination is required to support client goals & outcomes
Adult	Age range: 19-64 years old; Multiple care partners across sectors; overall poor coping; multiple complex psychosocial issues; unmanageable behavioral/mental health issues;
Senior	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
Palliative	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 < 6 mos.; Palliative Performance Scale (PPS) score (suggested guideline): 0-30%
Chronic	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 11-16; Moderate care coordination intensity is required to support client goals & outcomes
Adult	Age range 19-64 years old; Requires assistance to continue with age-related roles;
Senior	Age range: 65+ years old; Age related morbidities
Palliative	Pain and symptoms are manageable; predictable trajectory; high likelihood of death in preferred place; Prognosis >6mos; Palliative Performance Scale (PPS) score (suggested guideline): 40-60%
Community Independence	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 & outcomes
Supported Independence	Focused & time-limited engagement of services to promote safety & independence (anticipate discharge < 1 year but may be on longer); Proactive linkages to community support services, as applicable to prevent deterioration of function; RAI score 1-6
Stable at Risk	Focused engagement of services to promote safety & independence (uncertain care trajectory); Proactive linkages to community support services, as applicable, to prevent deterioration of function; RAI score 7-10;



Short Stay	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.
Acute	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:
Oncology	High capacity to transition to self-care; May require CCAC services 90-180 days (or beyond); Active treatment for cancer <u>with or without</u> metastatic disease
Rehabilitation	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.
Wound	High capacity to transition to self-care; Focus on intervention is wound care; Typically new admissions; Use of pathways, as applicable.
Well	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

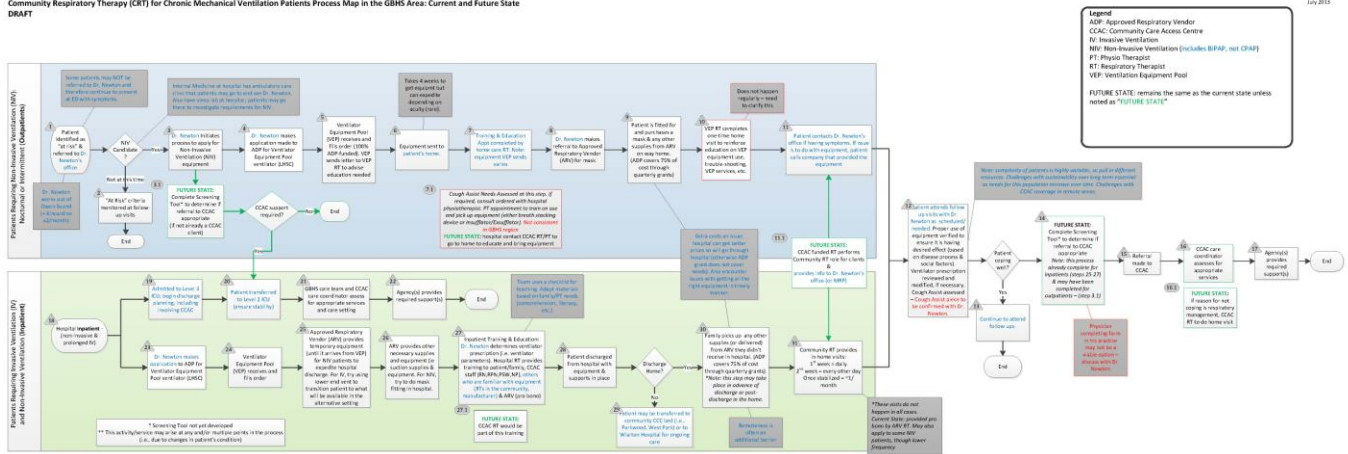


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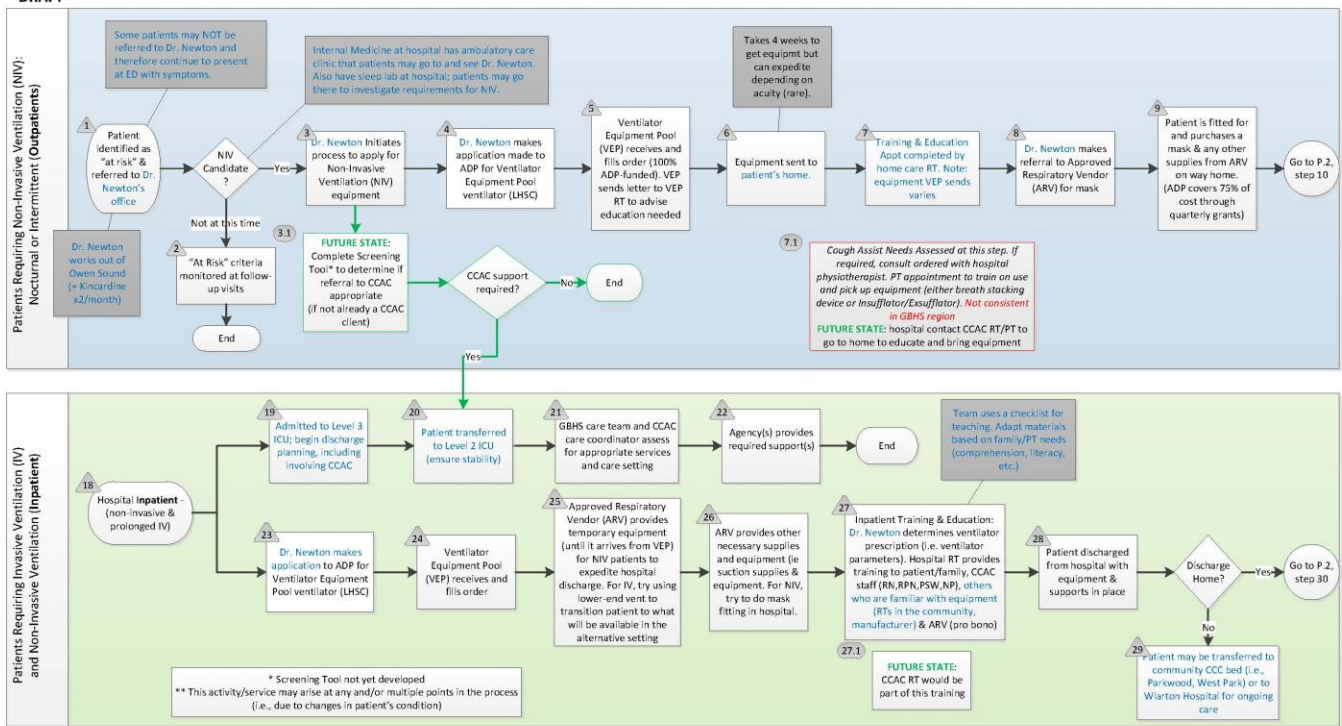
APPENDIX D – Community Respiratory Therapy – process flow map showing how Community Respiratory Therapy is integrated into the on-going care process

Grey Bruce Health Services – Owen Sound

Community Respiratory Therapy (CRT) for Chronic Mechanical Ventilation Patients Process Map in the GBHS Area: Current and Future State
DRAFT

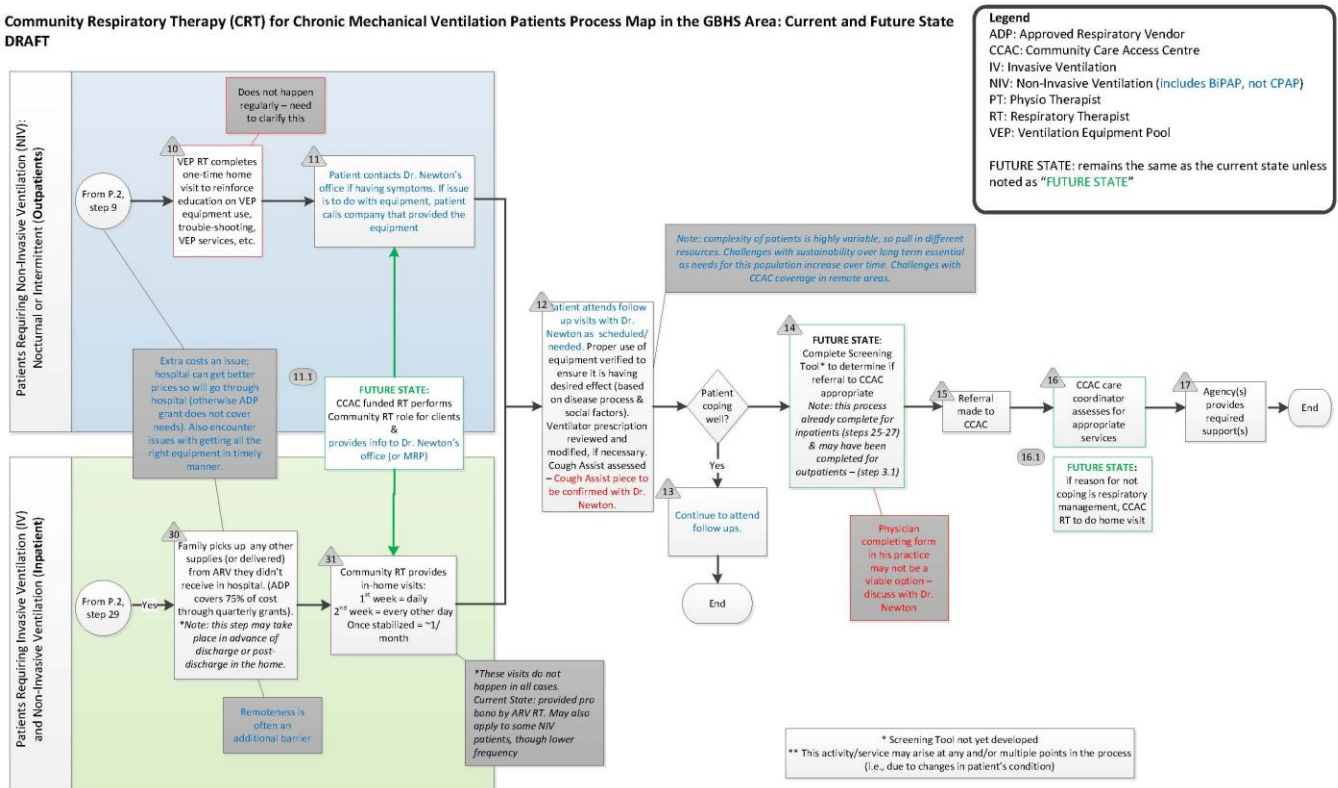


Community Respiratory Therapy (CRT) for Chronic Mechanical Ventilation Patients Process Map in the GBHS Area: Current and Future State
DRAFT



Grey Bruce Health Services – Owen Sound

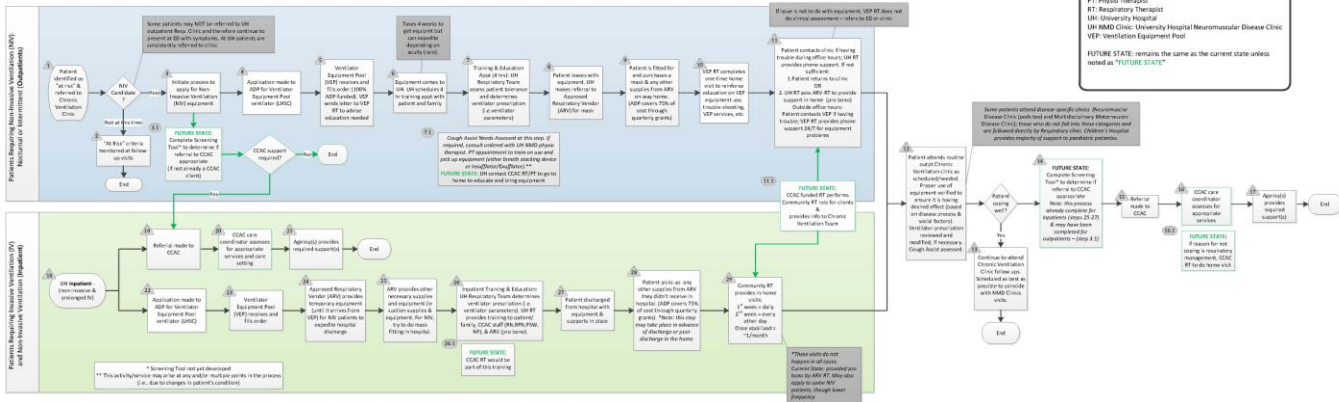
Community Respiratory Therapy (CRT) for Chronic Mechanical Ventilation Patients Process Map in the GBHS Area: Current and Future State DRAFT



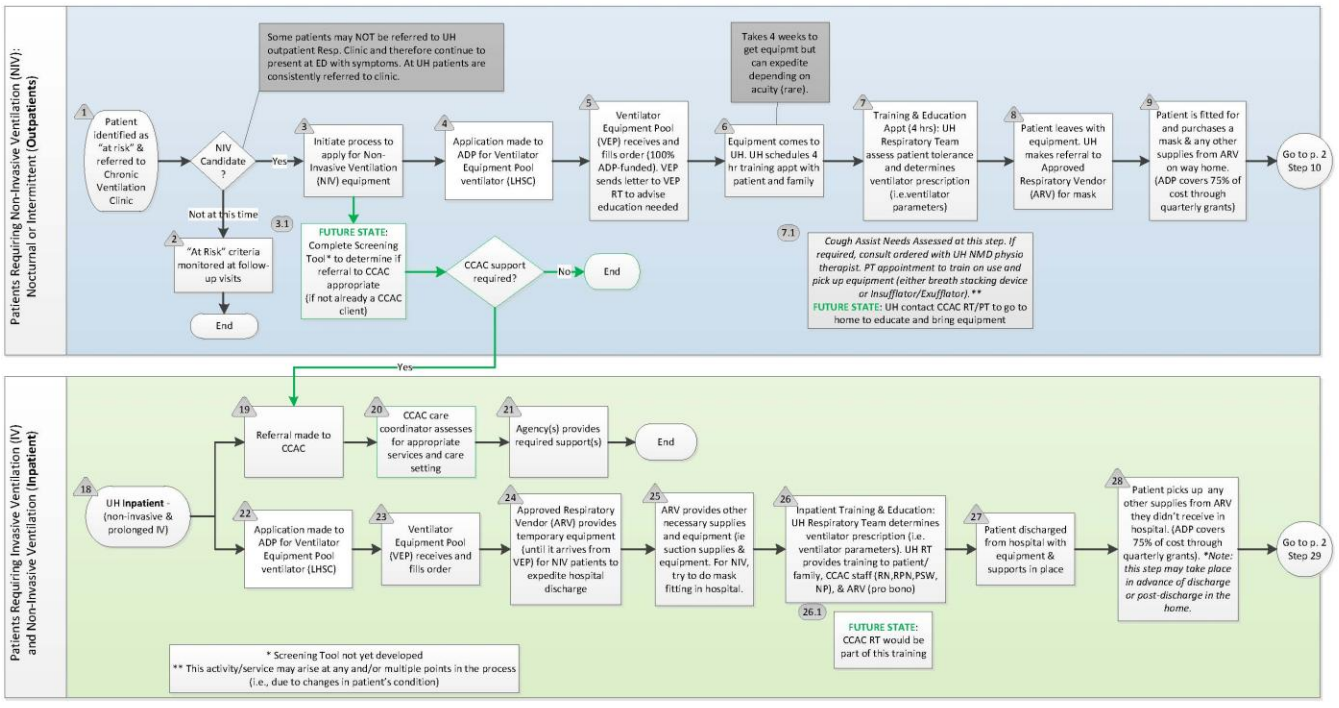
London Health Sciences Centre

Community Respiratory Therapy (CRT) for Chronic Mechanical Ventilation Patients Process Map: Current and Future State

July 2015

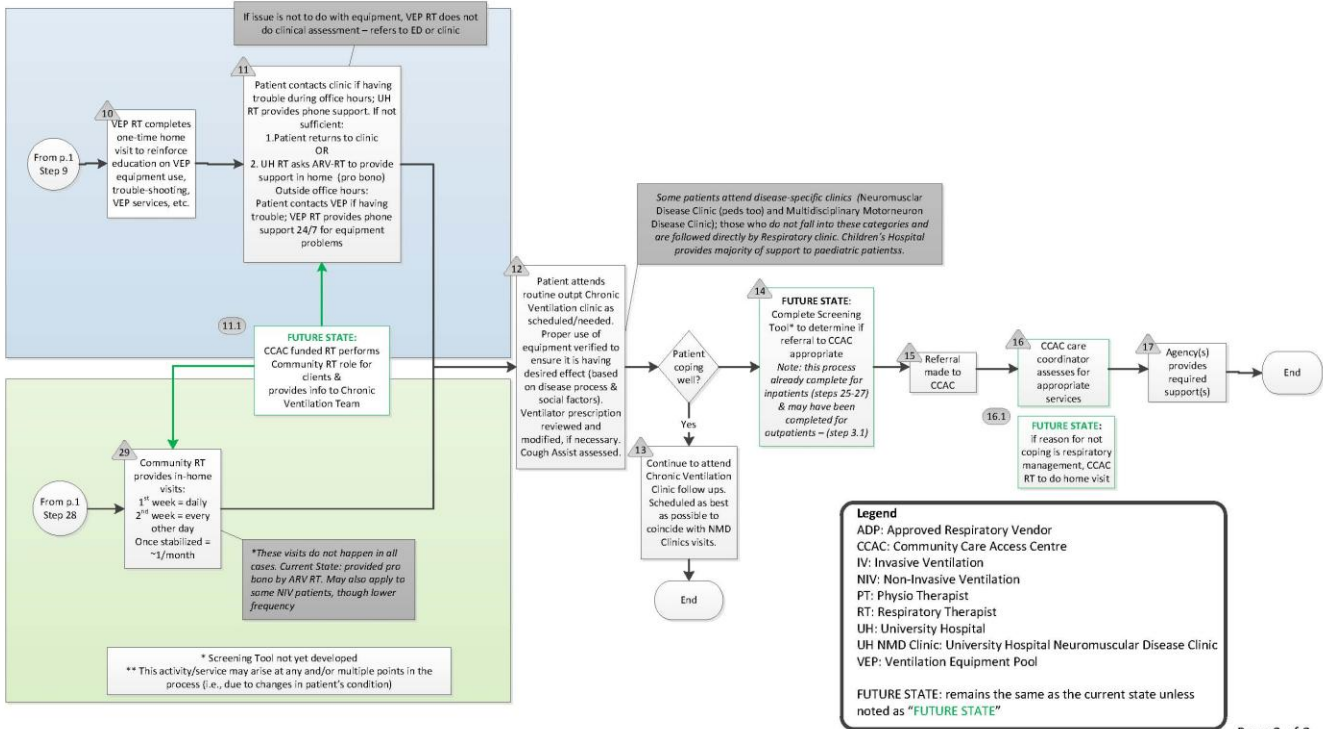


Community Respiratory Therapy (CRT) for Chronic Mechanical Ventilation Patients Process Map: Current and Future State



London Health Sciences Centre

Community Respiratory Therapy (CRT) for Chronic Mechanical Ventilation Patients Process Map: Current and Future State



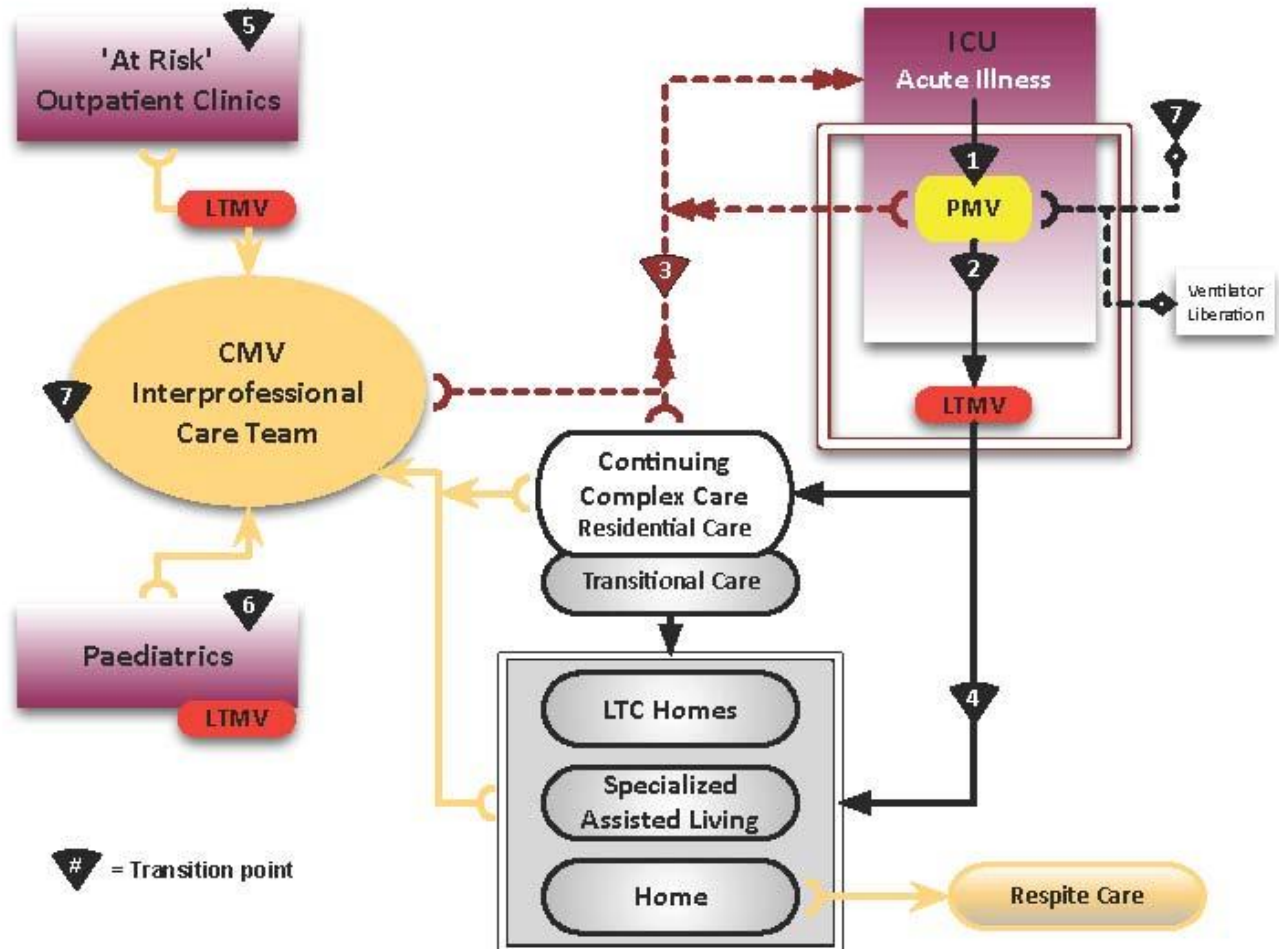
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APPENDIX E - Operational Metrics for the Appropriateness of Care Transitions














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, Respiriologist LHSC



Legend

CMV = Chronic Mechanical Ventilation	 Transition from ventilation in the acute phase of illness to PMV
LTMV = Long-Term Mechanical Ventilation	 Transition from PMV to LTMV
PMV = Prolonged Mechanical Ventilation	 Transition from PMV or LTMV to acute critical care ventilation (reverse transition)
LTC = Long-Term Care	 Transition from institutional care to care within community (home/assisted living)
 = Transitional Respiratory Care Unit	 Transition from 'at-risk of' to 'requiring' LTMV
 = Community Care	 Transition from pediatric to adult services
 = Scheduled followup care	 Transition from active treatment to end of life care for PMV or LTMV
 = Ventilator discontinuation	
 = Care venue transition	
 = Acute care transition	

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, Respiriologist LHSC)

Transition Criteria

(Reference: Definitional Criteria for Patient Transitions Relevant to Prolonged and Long-term Mechanical Ventilation: A Delphi Study: Louise Rose 2013; submitted for publication).

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

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

2. Transition from PMV to LTMV

Criteria that *should* define transition

- Patient stability from a physiological perspective
- Establishment of a transition plan
- Option of withdrawal of care is discussed
- Acceptance and motivation of the patient based on informed choice
- Redefinition of the goals of care/care plan
- Patient’s prognosis
- Requirement for invasive mechanical ventilation on an indefinite basis
- Patient care needs can be managed in a community or a long-term care facility
- Capability of the healthcare team to manage LTMV
- Acceptance/motivation of family/informal caregivers based on informed choice
- Likelihood of acceptable quality of life

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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