



Welcome to the Prolonged-Ventilation Weaning Centre

Patient and Family Guidebook



Provincial Weaning Centre of Excellence

For Prolonged Ventilation

Our Vision

No Long Term Ventilation Patients in any Intensive Care Unit in Ontario

Our Mission

To establish a multi-nodal, knowledge-based community of clinical, educational and research practice excellence, incorporating the expertise throughout the Provincial Long Term Ventilation Strategy and beyond.

Our Centre of Excellence includes:

- Prolonged-ventilation Weaning Centre (PWC)
- Long-term Ventilation Care Unit (Complex Continuing Care)
- Tracheostomy Care Team
- Educational Program
- Research Program

Prolonged-Ventilation Weaning Centre

Welcome to the Prolonged-ventilation Weaning Centre (PWC) at Michael Garron Hospital (MGH), previously Toronto East General Hospital. The move to another hospital or out of the Intensive Care Unit might worry you and your family as it is a big change. We will work with you to help you recover and ensure that you have the best possible chance of weaning from the ventilator. (I.e. breathing on your own without the need of the breathing machine).

Our Message to Family Members and Friends

As a family member or a significant person in a patient's life, you may experience feelings of helplessness or loss of control when your loved one is in our centre. This brochure is designed to help you cope with this very difficult situation and to guide you in helping your loved one meet their care goals.

We created this booklet to address some common questions about our centre here at MGH. Please do not hesitate to ask us any additional questions and to share your concerns. *We are here for you!*

What is the PWC?

The PWC is an eight-bed, specialized center at the MGH for adult patients who have recovered from the acute illness that caused their admission to an intensive care unit (ICU), but remain on a breathing machine (ventilator) for more than 3 weeks and who wish to try to breathe on their own.

Our center accepts referrals from any ICU in Ontario, but largely from the Greater Toronto Area and nearby areas of Southern Ontario. Our patients stay for a maximum of 12 weeks and undergo an individualized rehabilitation program to assist them in breathing free from the ventilator.

The types of patients that we consider for admission into our program include adults who:

- remain on a breathing machine for more than 14 days
- can participate in and direct their own care
- are stable apart from their need for a breathing machine
- have discussed and documented a plan about how they wish to be cared for (advance directive)
- do not require kidney replacement treatment (dialysis)
- have feeding support in place
- have treated and controlled infections
- do not have a clearly irreversible disease such as metastatic cancer or advanced dementia

The PWC is not an ICU. Our centre is located within a hospital floor that specializes in the management of respiratory disease. Unlike an ICU, our patients share their nurse with two or more other patients. This is because our patients are no longer critically ill and do not require one-to-one monitoring. Our

patients' vital signs are monitored every 4 hours or more frequently if needed. Oxygen levels are monitored during the weaning process.

The Program

We use a patient and family-focused, team-based approach to help our patients breathe by themselves that decreases help from the breathing machine in a step-by-step manner, known as weaning. Once accepted into our program, we give patients 24-48 hours before starting the weaning program to allow them to adjust to their new environment. During this time, the interprofessional care team will meet with new patients and develop a plan of care for meeting care goals that addresses the needs and wishes of the patient and their family members.

We believe our success at weaning patients with difficulty breathing independently of a machine is due to:

- A focus on collaboration and communication with the interprofessional team, patients and their families
- Attention to a calm and quiet environment
- Consistent processes for weaning and physical therapy
- Commitment of our patients to participate in weaning and physical therapy

Individualized Care Plan

It is important to remember that each of our patients is different and has a unique set of strengths and challenges that we carefully consider during development of their individualized care plan. Our team partners with patients and their families to create a care plan for weaning from the ventilator, mobilization, and the daily routine. Daily goals are recorded on a white board in each room and the care team makes every effort to inform patients of upcoming tests and procedures. We have our best success helping patients meet their goals when we partner with them.

Repatriation

Our program is a **maximum** of three months in duration. Many of our patients do not stay the full three months either because they are weaned off the breathing machine or our care team determines that, despite our greatest efforts, weaning is not possible.

If weaning occurs usually we are also able to remove the tracheostomy tube (breathing tube placed in neck), feeding tubes and intravenous lines.

Sometimes a patient is only partially weaned from the breathing machine and may require ongoing breathing machine support during the night or part of the day.

Although most patients are discharged back to their referring hospitals, some are discharged to rehabilitation facilities, nursing homes, chronic care institutions, or long-term ventilation centers. A small number of patients are discharged directly to home.

Palliative Care

As part of our comprehensive patient-focused care, we also provide palliative care for patients and their families in end-of-life situations. Our team includes physicians, nurses, a bioethicist, transition navigator, and spiritual care team members who can assist the patient and their family understand and cope with decisions around direction of care and palliation. If our patients decide that ongoing ventilation is not part of their wishes, we ensure that withdrawal of the breathing machine is as comfortable as possible, focuses on patient and family wishes, and a peaceful death.

The PWC Team

Our Interprofessional team includes doctors, nurses, respiratory therapists, personal care workers, physiotherapists, occupational therapists, speech language pathologists, dietitians, pharmacists, social workers, researchers, inter-faith chaplains, a bioethicist, and volunteers.

Physicians

Doctors, who are specialists in breathing disorders (Respirologists), direct the day-to-day medical care with the help of other specialists who are consulted when needed. As many of our patients experience anxiety and depression, a psychiatrist assesses all patients as part of our routine admission process.

Nurse Practitioner

The Nurse Practitioner (NP) is a nurse with additional training and license in an extended class. The NP works with the interprofessional and medical team to help plan and coordinate the overall and day to day care of the weaning center patients

Nursing Care Team

The nursing team provides moment-to-moment direct patient care with a registered nurse assigned daily as the team leader. Nursing care is evidence based and focused on reducing the risk of the many complications associated with the prolonged hospitalization and need for a breathing machine, including anxiety, infections, blood clots, bleeding, and heart attacks.

Respiratory Therapists

Registered Respiratory Therapists are experts in weaning and help to progress our patients along the weaning continuum from complete reliance on the machine to breathing without assistance. They also manage the breathing machine and oxygen equipment.

Physical Therapists, Occupational Therapists and Occupational or Physical Therapy Assistants

A dedicated Physical Therapist, Occupational Therapist, and Physiotherapist/Occupational Therapy Assistant work with our patients to help regain and/or maintain physical strength and functioning, enable individuals to improve and/or engage in functional movement, and optimize breathing as a primary focus. This team works closely with respiratory therapists and nurses to coordinate patient

care cohesively. These therapists undertake a holistic approach to early mobilization and understand that each patient is unique and their care is individualized..

Registered Dietitian

A registered dietitian works with our patients to select the most appropriate route of nutrition support and to help with the transition to an oral diet as soon as it is safe to do so in consultation with a Speech and Language Pathologist. Our patients usually have feeding tubes in the abdomen called PEG tubes. This tube delivers nutrition while minimizing the risk of respiratory infection. Once our patients are established on an oral diet, the PEG tube can be removed.

Pharmacist

A registered pharmacist works with the team and with patients to ensure continuity and optimization of safe pharmacological treatment.

Speech and Language Pathologist

Tracheostomy/ventilator dependency alters normal swallow function and the ability to speak. A Speech-Language Pathologist works with our patients and the team to monitor and manage communication and swallowing during the weaning process.

Inability to communicate can be frightening and frustrating. Our Speech and Language Pathologist provides alternatives to speaking such as communication boards. When our patients are further along in the weaning process speaking can be restored with an attachment to the tracheostomy called a Passy-Muir or speaking valve.

Transition Navigator

Upon admission to our centre, our will arrange an interview with you and your family. We attempt to schedule family meetings as required, and at four, eight and 12 weeks from admission to our program to address questions and provide updates on patient progress.

Spiritual Care

Spiritual Care team members are a resource for patients and family members to help support during times of illness and stressful times. Seeking to build a relationship of trust through compassionate presence, they are involved in the provision of holistic care. They work collectively and collaboratively alongside other health care professionals. Their support may focus on the emotional and spiritual adjustments to illness, decision making regarding end of life care, a search for meaning and purpose through difficult times, help in crisis situations, including family/relational issues, and loss and grief.

Other Supports

MGH has Volunteers/Therapeutic Touch available for our patients and families. Our care team facilitates access to these options.

Research Coordinators

MGH is a teaching hospital and the PWC is the leading program in Ontario that specializes in weaning from the ventilator. To help us improve patient experience our patients may be approached to be

involved in our research program. Our research studies aim to improve our care and clinical protocols and to increase the chances of successful weaning from the ventilator.

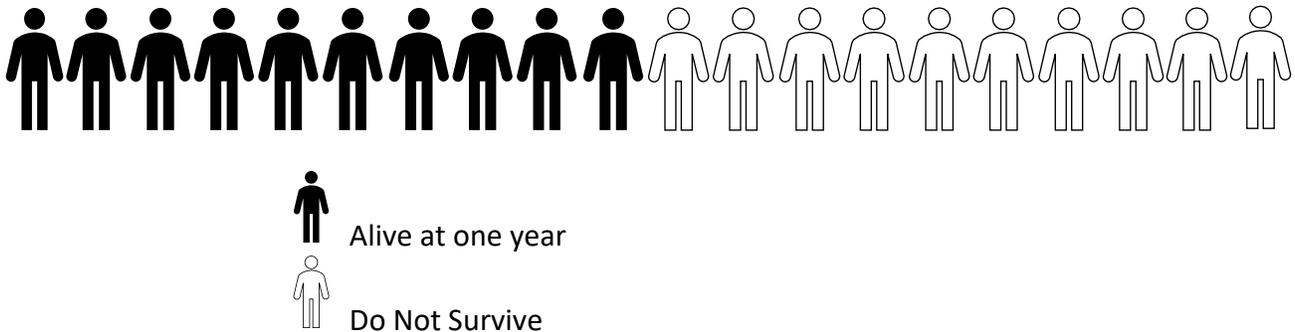
Complications of Prolonged Ventilation and Critical Illness

What is Chronic Critical Illness?

Although most patients who need care in the ICU get better quickly and no longer need a ventilator or other critical care treatments after a few days, some patients remain critically ill and have trouble breathing on their own, without a machine, for a much longer time. These patients have chronic critical illness, which usually involves many body systems and organs.

Is Chronic Critical Illness a Serious Condition?

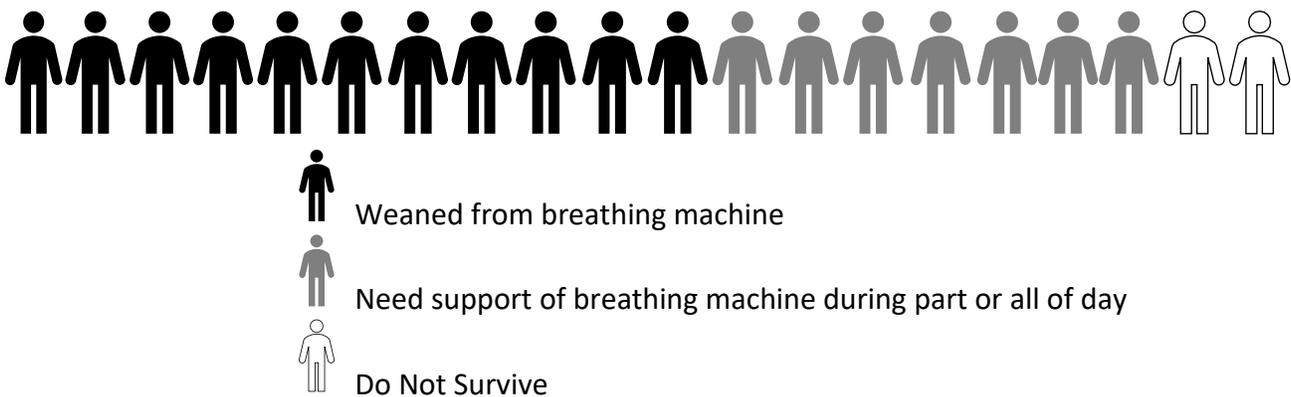
Yes. Patients who survive initial treatment in the ICU remain at risk of dying. We worry most about patients who are elderly and who still need life support, like a breathing machine, even after many attempts to remove the need for life support. Most patients have trouble fighting infections and more than half of patients with chronic critical illness die within six months.



In general, out of 20 ICU patients requiring a breathing machine for more than three weeks, only ten will be alive in one year's time.

Do Chronically Critically Ill Patients Regain their Ability to Breathe on their Own?

As time passes, the chances of being free from the ventilator decrease. Each patient is different and it is not always easy to predict how things will turn out. However, in general, out of 20 patients admitted to our centre, approximately 11 will wean from the breathing machine, seven will need some breathing machine support during part or all of the day and two will not survive the complications of prolonged ventilation resulting from chronic critical care illness.

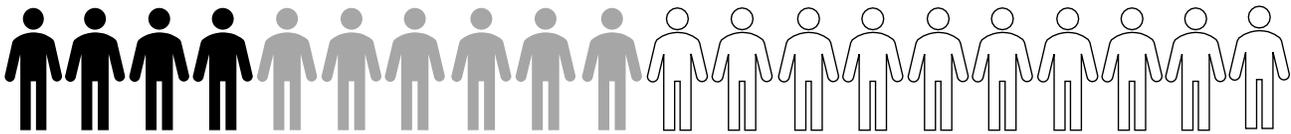


What is the Treatment for Chronic Critical Illness?

Treating chronic critical illness involves caring for the total person rather than using a single medication or procedure. The goal of care is to free patients from the breathing machine and return them to their previous ability to take part in everyday activities.

How Long Does It Take to Recover from Chronic Critical Illness?

Recovery from chronic critical illness takes up to one-and-a-half to two years. Complete recovery to a level before critical illness is uncommon. Most patients will have some degree of reduced muscle strength and balance as well as difficulties with emotions, thinking, sleeping and the ability to care for themselves on their own.



Alive and independent at one year



Alive at one year with significant dependence



Do Not Survive

Potential Complications of Prolonged Ventilation

Ventilator Associated Pneumonia (VAP)

Ventilator associated pneumonia (VAP) refers to a lung infection occurring when on the ventilator. Many of our patients experience VAP during their ICU admission and are still at risk for this in the PWC. If a patient develops VAP, we may temporarily interrupt the weaning program and start antibiotic treatment. Other treatments that reduce the risk of VAP include tooth brushing, regular mouth care with an antiseptic called “Chlorhexidine”, and keeping the head of the bed up above a minimum angle of 30-45 degrees as much as possible to prevent saliva entering the lungs.

Urinary Tract Infection (UTI)

A urinary tract infection (UTI) is an infection in the urinary system, which includes the bladder (stores the urine) and the kidneys (filters blood to make urine). Germs (for example, bacteria or yeasts) do not normally live in these areas; but if introduced, can cause an infection. UTIs are treated with antibiotics. Health care providers can lower the risk of UTIs by always washing their hands, and removing the bladder catheter as soon as it is no longer needed.

Blood Stream Infections (BSI)

Many of our patients come from the ICU with a peripherally inserted central catheter (PICC) in their arm. This catheter is often used to draw blood samples, or give fluids or medications. As with any invasive line, there is a risk of infection. A catheter-associated infection is serious, but can be successfully treated by removing the catheter and giving antibiotics.

Oral hygiene (Thrush and Dry Mouth)

When the body’s immune system (body’s defenses) is weakened, a mouth infection with a common fungus called “thrush” might develop and is usually treated with anti-fungal mouth rinse.

Dry mouth is a common symptom among our patients. Naturally, our patients often ask for water or drinks to alleviate mouth dryness. However, the potentially life-threatening risk of liquids entering the lungs from drinking by mouth means that it is not recommended until careful assessment by our Speech and Language Pathologist. Fortunately, frequent mouth care, lip balm, artificial saliva spray and oral moisturizing gel can help soothe, protect and restore moisture to mouth. Any caregiver (family or staff) can help with this.

Anxiety

All of our patients experience anxiety, especially during weaning. We use a wide variety of methods to lessen anxiety including distraction (TV, music, volunteers) and promotion of a calm/quiet environment with a regular sleep pattern. Family members are often invaluable in helping us identify how best to manage anxiety.

Pressure Ulcers

Skin breakdown may occur during prolonged hospital stay with a life-threatening illness, particularly in bony or high pressure areas such as the lower back, heels and elbows. Constant monitoring of the skin, good nutrition, frequent repositioning in bed and mobilization (sitting, standing, & walking even on the ventilator), are some of the ways that we lower the risk of developing pressure ulcers.

Swallowing Difficulty

After being on a breathing machine for a number of weeks, learning to swallow again can often be difficult. Not only are the swallowing muscles weak but the tracheostomy tube in the neck may make it harder to swallow normally.

Life after the PWC

After prolonged critical illness it is not uncommon for people to experience memory loss (amnesia), depression, anxiety, or even panic attacks. We encourage our patients to let their family doctor or nurse practitioner know if this is happening so that they can help with recovery. Primary care providers can also help with lifestyle improvements including quitting smoking, adjusting diet and expanding physical activities

Smoking

For patients that previously smoked, this is a real opportunity to quit smoking altogether. The single most important thing to help lungs heal is to not smoke. In addition, smoking can interfere with wound healing and appetite. Each time a smoker says no to a cigarette, 5 minutes are added to their life. Finding a substitute for smoking such as walking if able, chewing sugar-free gum, exercising, or starting a new activity is important. The nurses in the PWC can help patients connect to Smokers Help Line, a free support service for people at any stage of the quitting journey. Our doctors/nurse practitioner can discuss other options to help stop smoking for good.

Eating/Nutrition

Eating habits will have been affected by critical illness because of dietary alterations or the medications received. Our patients frequently do not have the same appetite or find that food tastes different. Temporary changes may include foods tasting saltier, sweeter, or taking on an unusual metallic taste. Until appetite returns to normal, it may be easier to eat small frequent meals of favourite foods, supplemented by healthy snacks between meals. Take time to eat and enjoy a variety of foods daily. Depending on your specific nutritional needs, make certain to include fruits, vegetables, dairy products, grains, and protein because a well-balanced diet will help build strength, fight infection, and assist bowels to move and promote mental health

Exercise

Daily exercise will help reduce stress and anxiety while helping regain strength and appetite. Initially it is common to become easily tired because of the effects of illness, medications, or smaller food intake. Muscles may be smaller and weaker after being critically ill. Any exercise is good, and it is best to gradually increase activity levels. We recommend talking to a family doctor or other healthcare professional about appropriate exercises.

Sex

It is normal for patients and their partners to have a decrease in sex drive after a critical illness. Lack of interest and feeling too tired for sex are common. It is important to discuss your feelings to keep the lines of communication open. Remember that holding hands, massaging, cuddling, and comforting are all ways to be intimate.

Stress/Relaxation

Certain levels of stress can be healthy and, in fact, help accomplish daily tasks. As stress levels rise tenseness, anger, tiredness, and irritability are experienced. Being under constant stress can increase the risk for subsequent illness. Relaxation techniques to manage stress include:

- Deep breathing exercises in a quiet location.
- Taking a “mental vacation” by closing your eyes and imagining yourself in a place that you like.
- Setting aside time each day to do something you enjoy.

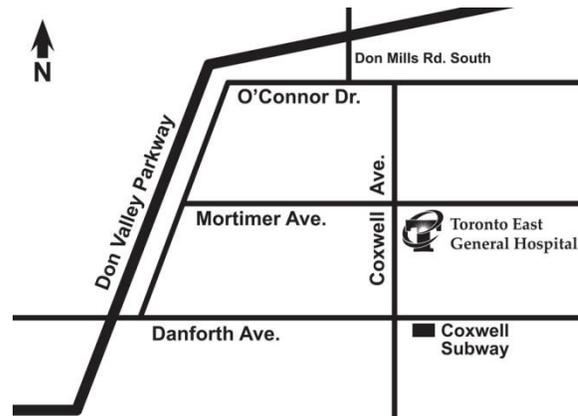
For the Family - Taking Care of Yourself

Your wellbeing is important to your loved one and to us. The following recommendations are designed to provide you with strategies to help you take care of yourself during this difficult time.

- Proper food and sleep will improve your ability to listen and understand the information that will be shared with you.
- Stressful situations as well as staying awake all night, every night, will eventually wear on you, and can make you prone to illness.
- Try to eat healthy foods regularly. Eat something every 3 to 4 hours.
- Whenever possible, get up and walk around. Exercise is very important to maintaining emotional health.
- Gather support from family and friends
- Prepare yourself for setbacks. Some days will be good and some will be bad. Concentrate on the steps taken forward and view the steps backward as hurdles that can be overcome
- A notebook can help to keep track of information and can also provide encouragement as small improvements are seen over time

About Michael Garron Hospital

Michael Garron Hospital is located in South East Toronto, Ontario. The PWC is located on the 7th floor in the H wing. We are easily accessed by TTC via the Bloor/Danforth line.



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Compliments or concerns please contact our Patient Relations Consultant: (416) 469-6096, email: ptrep@tehn.ca

For visitor expectations, amenities, and services (e.g. food, parking, green space, and parking) please visit our website www.tehn.ca

Glossary

Here are brief explanations of some terms you may hear. Do not hesitate to ask for further clarification from your care team.

Advance directives Instructions from a patient (spoken or written) about the treatments they would want or not want and about who should make medical decisions if the patient cannot do this themselves. Advance directives include living will, durable power of attorney for health care and health care proxy.

Arterial blood gas (ABG, blood gas, gas) Blood test on a sample taken from an artery that helps the healthcare team know how well a patient is breathing by measuring the amounts of oxygen and carbon dioxide.

Catheter (tube, line, drain) Plastic tube placed in a blood vessel (vein or artery) or another part of the body (e.g., bladder catheter to drain urine).

Central line (IJ, subclavian line, femoral line, PICC) Special intravenous catheter in a large vein (usually near the neck or collar bone) to give fluids, medications, or nutrition or to measure blood pressures in and around the heart.

Chronic Critical Illness (CCI) CCI is a discrete and complex syndrome of physiologic abnormalities, organ dysfunction, and neuroendocrine and immunologic dysfunction.

CPR (cardiopulmonary resuscitation) A procedure to try to restore breathing and blood flow if a patient has a cardiac arrest—that is, if the patient’s heart and breathing stop. This procedure combines pressing on the chest and giving rescue breathing (in the ICU, this is done by machine) and administering medications.

Critical Care Outreach Team (outreach team) A team of intensive care nurses, respiratory therapists, and doctors who might come to assess you if you have respiratory or cardiac (heart) distress (trouble).

Do-not-resuscitate (DNR, do-not-attempt resuscitation, DNAR) A directive (order) that instructs the healthcare team not to attempt to restart the patient’s heartbeat or breathing through CPR.

ECG (EKG) Equipment that monitors and shows the heart rate and rhythm.

Endotracheal tube (ET tube) Breathing tube that is placed in the patient’s airway (trachea) through the mouth or neck and is attached to a mechanical ventilator (breathing machine) to help the patient breathe.

Face mask (oxygen mask, O2 mask) Plastic mask that is placed over the nose and mouth. The mask is attached to a plastic hose that gives oxygen (from a tank or wall source) to restore oxygen levels.

Isolation The term we use to describe wearing personal protective apparel when a PWC patient first arrives, until swab results return for colonization of antibiotic resistant microorganism colonization (e.g. MRSA, VRE, C diff., etc.).

Life-supporting treatment (life support) Treatment that can include mechanical ventilation (breathing machine), nutrition (feeding by tube or through the vein), intravenous hydration (fluid given through the vein), kidney dialysis, medicines to raise blood pressure and boost the heart rate, and other treatments to attempt to prolong life.

Nasal cannula (cannula) Plastic tube that fits around the head with two short prongs into the nostrils. It provides the patient with oxygen (from a tank or wall source).

Nasogastric tube (NGT, NG) A tube placed through the nose or mouth into the stomach. It is used to give medicines and feedings or to drain stomach contents.

Non-Invasive Ventilation (NIV) Assistance with breathing from a machine and mask.

Nocturnal Ventilation Invasive or Non-Invasive assistance with breathing at night.

Passy Muir or Speaking Valve This device is attached to the tracheostomy tube and redirects air flow through the vocal folds, mouth and nose enabling voice and improved communication.

PEG (percutaneous endoscopic gastrostomy) Tube placed through the skin and wall of the abdomen into the stomach to give feedings (and medicines) to patients who cannot take these by mouth.

Pulse oximeter (pulse ox, O2 sat monitor) Device placed on finger, toe, or earlobe to check how much oxygen is in the blood.

Suction Removal of secretions (phlegm or mucus) or drainage from the patient's airway (trachea) or other part of the body (e.g., stomach).

Tracheostomy (tracheotomy, trach) Surgical opening in the neck for insertion of a breathing tube into the patient's airway (trachea). This tube is attached to a mechanical ventilator (breathing machine) or an oxygen mask to help the patient breathe.

Trach mask A mask that is connected to an oxygen and humidification source that is placed over the tracheostomy.

Trach mask trial A pre-determined time set daily for weaning from the ventilator

Tracheostomy Care Team The team of doctors, respiratory therapists and other healthcare professionals who provide daily care to patients who have tracheostomies. This care involves monitoring, clearing of secretions within the tube by suctioning, routine changing of the tracheostomy tube, capping ("corking") of the tube to allow you to speak with your own voice, and, removal of the tube when it not required

Ventilator associated pneumonia (VAP) A potential complication (lung infections) of breathing on a ventilator.

Ventilator/respirator (vent, breathing machine, mechanical ventilator) Machine attached to the patient by a tube (in mouth, nose, or neck) to help the patient breathe.

Weaning Process of progressive reduction of the amount of breathing support provided by a ventilator

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**Please see our Website for information about our research and education programs.
www.tehn.ca**

References

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http://www.cdc.gov/hai/pdfs/bsi/BSI_tagged.pdf

www.rnao.ca

www.tehn.ca

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A Space for your notes and questions

Your Story

Please take a moment to share your story with us. We would like to hear about your experiences so that we can get to know you and enhance our care of the people who are our PWC patients. Thank you.