Goals of Care and Advance Care Planning in light of COVID-19

Since writing this on April 10, media has exploded with information about what we need to know to inform our Goals of Care or Advance Care Plan in light of COVID-19. Enlightened discussions about palliative care are being had in numerous settings. The information I provide here is well (and probably more eloquently) covered in the newspapers or relevant podcasts (like CBC's Dose and White Coat Black Art). Ventilation is no longer the only or preferred treatment.

1) A recent COVID-19 update from the Perth and Smiths Falls Hospital notes that patients who require higher levels of critical care (including longer periods of ventilator care) are transferred to Ottawa or Kingston. This is always the case and continues to be the practice.

2) Hospitals, like long term care homes, are severely limiting, sometimes completely prohibiting, all visitors. Including to those at end of life.

If you already have an Advance Care Plan, there is likely nothing extra that needs to be done other than ensuring your family and especially your Substitute Decision Maker know your plan and wishes. Your Plan will already be made based on your age and current health. If you or your loved one has expressed the wish not to be resuscitated nor to receive life prolonging measures but to opt for comfort and symptom management, then your direction is clear whether or not you contract COVID-19. When it comes to COVID-19, it appears that two main decisions are required: decide on mechanical ventilation and hospitalisation or palliative care whether you are at home (including senior's residence or long-term care) or in the hospital.

Advance Care Planning & Goals of Care Considerations

- COVID-19 is a virus that produces a viral pneumonia. At this time, there is no treatment for this viral pneumonia. There are only supportive measures such as ventilation.
- COVID-19 can affect the lungs in such a way that causes an overreactive immune response. When our immune system overreacts, it can cause its own problems such as organ damage and multisystem organ failure.
- Dying from COVID-19 is relatively quick because of the way the lungs fill up and the resulting multisystem organ failure.
- Dying from multiple organ failure may be a relatively painless way to die, but regardless, all end of life treatments are used to manage symptoms including pain medications

Ventilation

- Ventilation is life support and used as a last resort because the patient cannot breathe on their own. It is intended to oxygenate the lungs while allowing the body to rest and heal if possible. It does not cure the disease. The ventilator machine is artificially breathing for the patient by delivering small puffs of highly oxygenated air to the lungs.
- Ventilation is set up by Intubation. Intubation is a long tube that is inserted through the trachea and vocal cords to open the airway and is done under anesthetic (the person is put to sleep) or in the case of an emergency when an individual is in an unresponsive state (as otherwise they might fight it off).
- The process of inserting the tube and suctioning airways is uncomfortable and painful.
- The tube carrying air and extra oxygen to the lungs provides a pathway for dangerous germs. Many ventilated patients get a new lung infection.
- The ventilator can damage the lung tissue based on how much pressure is required to help oxygen get processed by the lungs. Coronavirus patients often need very high levels of both pressure and oxygen because their lungs have so much inflammation.
- Most people are on a ventilator for 7 – 10 days or longer. The longer a patient remains on a ventilator, the more likely they are to die.
- While on ventilation, the patient is sedated and will have a tube down their throat. They are not alert and are unable to communicate their wishes/needs; they are unable to take care of their own bodily functions

- In the case of the elderly and the medically fragile who may have more complicating health factors, critical care interventions can cause harm and suffering without providing meaningful benefit or allowing a person to survive this disease. These patients often do not survive the extended period required in ICU on a ventilator. If they do survive, the elderly patient does not often recover well from such an experience. There may be many negative side effects including: needing ongoing care due to "post intensive-care syndrome" - a combination of cognitive decline, psychiatric problems like depression and post-traumatic stress as well as muscular-skeletal weakness (deconditioning). Many of the patients who continue to live can't be taken off the mechanical breathing machines. Fifty percent of those over 70 who do survive are still severely disabled one year later.
- Many of the patients who continue to live can't be taken off the mechanical breathing machines.
- (An informative article on ventilation: www.nytimes.com/article/ventilator-coronavirus.html)

Palliative Care
Whether you or your loved one choose to be ventilated or not, they and/or their Substitute Decision Maker should immediately request a palliative care consult. You may want to enquire early on about receiving palliative sedation in the event your symptoms cannot be managed.

Staying at home or going to hospital
Decide whether you want to be treated by ventilation. If you do, then you will be taken hospital. Know that a hospital admission brings other risks, such as cross-infection from other viruses or bacteria and possibly additional stress of being in a crowded ICU. If you don't want to go to hospital, palliative care can be administered in the home (call Home and Community Care to arrange). Regardless of where you are, let your family and health care provider know your wishes. If you need to talk or need assistance to advocate for yourself, ask to speak to a palliative care social worker. You can also consult with and receive palliative care only (not curative care) if you are in the hospital.

If you are looking after a loved one who may be dying (due to COVID-19 or another reason) and their wish is to receive palliative care and to stay in the home, then:

Palliative care and dying at home

The family needs to be mentally and emotionally prepared not to call 911. The dying individual's needs for comfort and symptom management will be met. The Caregiver(s) need to arrange the following:

1. Organise a consult both with the Physician and Home and Community Care
2. Ensure that the Physician does the following:
    a) Provides an order for and the actual medications for end of life, called the Symptom Response Kit
    b) Fills out the EDITH (Expected Death In the Home) chart
    c) Provides the order to allow a nurse to pronounce death.
3. Ensure you have a Care Coordinator through Home and Community Care and that your loved one will be seen by p**alliative care** nurses (and PSW's) – ask for this specifically.

If your loved one dies at home with this plan in place, there is no need to call 911. You call your nurse who can pronounce death. You call the funeral home once you are ready to do so. There is no rush at this time.

Think you have COVID-19 symptoms? This is the process:
Do not visit an assessment centre unless you have been referred by a health care professional.
Do not call 911 unless it is an emergency.
Take the self-assessment