

# Palliative Care COVID-19 Communication and Symptom Guidelines

## Introduction

Palliative care has been described as an essential part of an integrated humanitarian response to global pandemics.<sup>1</sup> The province of Manitoba has regional palliative care programs that can be a resource to help with the care of COVID-19 patients and their families. This includes help for patients and families in the community, and also within primary, secondary and tertiary care centres.

This pandemic has created an extraordinary situation, where the numbers of patients around the world who have, or will, become ill is unprecedented. Information is quickly changing, and there are innumerable resources, making it difficult to determine which information is up to date or accurate. This document focuses on information about communication and symptom management.

We have tried to use the most up to date and accurate information. Please continue to refer to Shared Health at <https://sharedhealthmb.ca/covid19/covid19-updates/> for the most up to date information.

## The Role of Palliative Care

The palliative care team has many strengths that can be of use to support health care teams in their practice.

For example:

- A COVID-19 infection in a patient already registered on the palliative care program may have very dire consequences, and they may require the rapid reassessment of goals of care. Our palliative care team is well-suited to have these discussions and to support you in having these discussions.
- If isolation prohibits in-person visitation, our team is used to helping families have goals of care conversations over long-distance and in convoluted conversational situations. The use of different forms of virtual health, or telehealth, can be utilized and we can help problem solve some solutions with you.
- Patients with COVID-19 may have a variety of symptoms at all stages of the disease trajectory, and supportive and symptomatic care is the current standard. Palliative care has expertise in symptom management and can be of help in these situations.
- The palliative care team is involved in the palliative education of other health providers, and can continue to educate health care providers to provide symptomatic, and holistic, whole patient, care.
- Health care teams may be overworked and experiencing moral distress, grief and frustration. This can lead to fragmentation of working relationships. As a team that works well collaboratively, palliative care has the skills to help ourselves and others

through team support, spiritual care and guidance on self-care.<sup>2</sup> (adapted from csupalliativecare.org)

## **Communication about COVID-19**

Patients and their families are understandably concerned about the impact COVID-19 may have on them and their care-givers. We can support them by:

- Sharing up to date information about the virus and safety measures to reduce the risk of exposure, including physical distancing and hand hygiene
- Using language focused on living in the moment and “I wish” statements
- Acknowledging there may be trade-offs palliative care patients are willing to make, within the context of the pandemic, to improve their quality of life
  - This may include the trade-off of not coming into a hospital if it means experiencing separation from family because of severely restricted hospital visiting policies

## **Goals of Care Conversations**

Conversations about goals of care in COVID-19 are approached in a manner similar to other serious illness conversations. These conversations should include discussions about a patient’s diagnosis, prognosis, hopes, fears, and trade-offs they are willing to make for the possibility of more time. Once these are determined, a recommendation for goals of care is given, discussed with the patient and his/her family, and clearly documented in the chart.<sup>3,4</sup>

These conversations will vary, depending on the clinical circumstances, and the Serious Illness Conversation Guide, shown below, is an example of an excellent tool to help make them more effective and more meaningful. The survival rates for patients with severe illness are listed below to help frame the prognosis portion of a goals of care conversation.

## **Prognosis for Patients with Severe Disease (non-COVID -19)**

Even in the absence of COVID-19, there are unfortunately limits on what critical care can achieve. For example, a large multicentre Canadian study called the Recover Program Study, looked at the outcomes of patients who were in the Intensive Care Unit (ICU) for over a week. Of people older than 65 years who stayed in the ICU over 14 days on mechanical ventilation, 40% died within 12 months of discharge from the ICU and most of the 60% of patients that survived had severe and persistent functional dysfunction and cognitive impairment, including inability to problem solve and memory loss. Only 19% of all the patients older than 65 who were ventilated for more than 14 days were discharged home directly from the hospital.<sup>5</sup>

## Prognosis for Patients with COVID-19

Determining the prognosis for COVID-19 is challenging because we are still in the early stages of the pandemic. We are unsure exactly how many people have been in contact with the disease, making overall estimates of survival with this disease difficult. However, there is significant reason to be hopeful as we have seen estimates of overall survival improve, as our knowledge of the virus improves. We have also seen improvements in the ability to provide better symptomatic care for those affected by the virus. Below are some of the reported data as of April 22, 2020. As more knowledge becomes available, these statistics are likely to change.

- For 81% of symptomatic patients, COVID-19 causes mild disease<sup>6</sup>
- Mortality rates were initially thought to be between 3.6-5.7%<sup>7</sup>, but may now be closer to 0.3 - 0.99%<sup>8,9</sup> and are expected to drop further as we learn more about asymptomatic cases
- Mortality from COVID-19 currently seems to be higher in elderly patients and in patients with comorbidities<sup>7,10</sup>
- Mortality rates for patients on mechanical ventilators are high, but the data is constantly changing and is challenging to interpret. It is likely that these rates will improve as we continue to learn how to care for the critically ill COVID-19 patients.
  - Early reports out of China for patients on mechanical ventilators due to COVID-19, reported death rates of 81-97%<sup>11,12</sup>
  - One large study from the UK quotes the mortality rate as 66%<sup>13</sup>
  - Two recent papers out of the Washington State<sup>14,15</sup> suggest the mortality rates are between 47.9-52%<sup>14,15</sup> and a very recently released large study out of New York quotes a mortality rate of 88.1%<sup>16</sup>
  - One paper out of Italy suggested a mortality rate of at least 26%<sup>17</sup>
    - The papers from the US<sup>14,15,16</sup> and Italy<sup>17</sup> need to be interpreted with caution because many of the patients in these studies were still alive in the ICU at the time the papers were published, making true estimates of ICU mortality difficult to determine
    - The paper from the UK also reports a bias toward reporting patients with a shorter length of ICU stay<sup>13</sup>
  - Mortality estimates seem to vary relating to the age and comorbidities of the patients on the ventilators.<sup>7,13,15,16</sup> Younger patients in the UK study, aged 16-49, survived mechanical ventilation 76% of the time.<sup>13</sup>
  - At this time we do not have data on long term outcomes of the mental and physical health consequences for patients who survive mechanical ventilation.

See tables regarding prognosis below.

## Age and Disease Adjusted Likelihood of a Patient Surviving COVID-19<sup>7</sup>

### AGE<sup>1</sup>

<b>AGE</b>	<b>DEATH RATE</b> <i>Confirmed Cases</i>	<b>DEATH RATE</b> <i>All Cases</i>
80+ years old	21.9%	14.8%
70-79 years old		8.0%
60-69 years old		3.6%

### PRE-EXISTING CONDITIONS<sup>2</sup>

<b>PRE-EXISTING CONDITION</b>	<b>DEATH RATE</b> <i>Confirmed Cases</i>	<b>DEATH RATE</b> <i>All Cases</i>
Heart disease	13.2%	10.5%
Diabetes	9.2%	7.3%
Chronic lung disease	8.0%	6.3%
High Blood Pressure	8.4%	6.0%
Cancer	7.6%	5.6%
no pre-existing conditions		0.9%

**Table 3 Critical care outcomes, by patient subgroup**

Patient subgroup	Patients with confirmed COVID-19 and critical care outcome reported		Patients with viral pneumonia (non-COVID-19), 2017-19
	Discharged alive from critical care	Died in critical care	Died in critical care
	n (%)	n (%)	(%)
<b>Age at admission to critical care</b>			
16-49	28 (75.7)	9 (24.3)	(9.9)
50-69	43 (59.7)	29 (40.3)	(23.4)
70+	15 (26.8)	41 (73.2)	(31.6)
<b>Sex</b>			
Female	35 (62.5)	21 (37.5)	(19.7)
Male	51 (46.8)	58 (53.2)	(24.3)
<b>BMI</b>			
<25	33 (57.9)	24 (42.1)	(23.6)
25 to <30	28 (58.3)	20 (41.7)	(23.6)
30+	18 (39.1)	28 (60.9)	(18.6)
<b>Assistance required with daily activities</b>			
No	70 (56.5)	54 (43.5)	(20.1)
Yes	12 (34.3)	23 (65.7)	(28.1)
<b>Any very severe comorbidities*</b>			
No	76 (52.4)	69 (47.6)	(19.4)
Yes	7 (41.2)	10 (58.8)	(34.1)
<b>Received advanced respiratory support</b>			
No	49 (80.3)	12 (19.7)	(10.3)
Yes	33 (33.7)	65 (66.3)	(36.1)

Note: Owing to the emerging nature of the epidemic, the sample of patients represented in this table is biased towards patients with *shorter* lengths of stay in critical care prior to discharge or death.

\* Very severe comorbidities are defined as: Cardiovascular: symptoms at rest; Respiratory: shortness of breath with light activity or home ventilation; Renal: RRT for end-stage renal disease; Liver: biopsy-proven cirrhosis, portal hypertension or hepatic encephalopathy; Metastatic disease: distant metastases; Haematological malignancy: acute or chronic leukaemia, multiple myeloma or lymphoma; Immunocompromise: chemotherapy, radiotherapy or daily high dose steroid treatment in previous 6 months, HIV/AIDS or congenital immune deficiency

It is important to remember that prognosis data does not predict outcomes for individual patients, and each patient must be assessed individually.

Goals of care **discussions** should ideally include prognosis data, if it is known, to best inform a patient and his/her family about **potential** outcomes. Goals of care **decisions** should be based on a collaborative approach that incorporates patient and family values, hopes, and any anticipated trade-offs that might be needed to achieve a health care goal. An approach to a COVID-19 goals of care conversation, that incorporates discussions around potential health outcomes, is presented below.

# Serious Illness Conversation Guide Adapted for COVID-19 From Fraser Health <sup>3</sup>

(MOST = Medical Orders for Scope of Treatment)

## SERIOUS ILLNESS CONVERSATION GUIDE A CONVERSATION TOOL FOR CLINICIANS Adaptation for COVID-19



The purpose of this scripted guide is to discuss potential outcomes of possible COVID-19 infection with at risk adults prior to a health crisis, including the elderly, those with chronic conditions (eg. heart/lung/renal disease, diabetes) or immunocompromised patients (eg. cancer, HIV/AIDS, transplant recipients). The intention is to open up dialogue and to introduce possible limitations to critical care interventions - eg. they may not be a candidate for ventilation, or for transfer to hospital. It is not intended to be a conversation to convince patients/clients to change their MOST status. This guide is to learn more about patients.

CONVERSATION FLOW	GUIDED SCRIPT
<p>1. <b>Set up the conversation</b></p> <ul style="list-style-type: none"><li>• Introduce purpose</li><li>• Prepare of future decisions</li><li>• Ask permission</li></ul>	<p>"I'd like to talk with you about COVID-19 and what may be ahead for you and your care. I would also like to hear from you about what is important to you so that we can make sure we provide you with the care you want if you get sick with COVID-19 - <b>is this okay?</b>"</p>
<p><i>Transition conversation to Step 2. Utilize paraphrasing and demonstrate empathy to let them know they've been heard.</i></p>	
<p>2. <b>Assess COVID-19 understanding and preferences</b></p>	<p>"What is your <b>understanding</b> about COVID-19 and how it is affecting at risk people?" "How much <b>information</b> would you like from me about COVID-19 and what is likely to be ahead if you get sick with it?" "How are you <b>coping</b> during this time of uncertainty?"</p>
<p><i>Transition conversation to Step 3. Utilize paraphrasing and demonstrate empathy to let them know they've been heard.</i></p>	
<p>3. <b>Share prognosis</b></p> <ul style="list-style-type: none"><li>• Share prognosis</li><li>• <b>Caution: purpose is not to provide patient education</b></li><li>• Frame as a "wish...worry" "hope ... wonder" statement</li><li>• Allow silence, explore emotion</li></ul>	<p>"I want to share with you our current <b>understanding</b> of COVID-19 and how it affects people at risk, specifically those like you with _____ (specific health condition(s), eg. heart/lung/renal disease, cancer, diabetes, etc.)."</p> <p>"COVID-19 is a virus that spreads through contact with liquid droplets when someone coughs or sneezes, often entering through our eyes, nose or throat if you are in close contact. We know that it is particularly serious for vulnerable people, especially for those who have other health problems. It can also cause other very severe problems."</p> <p>"It can be difficult to predict what will happen if you get sick with COVID-19. I <b>hope</b> it would not be severe and that you will continue to live well at _____ (current place of residence: home, assisted living, long term care, etc.)."</p> <p>"But I'm <b>worried</b> that as an adult with other health problems, you could get sick quickly and that you are at risk of dying. I think it is important for us to prepare for that possibility."</p>
<p><i>Transition conversation to Step 4 by allowing for silence. Consider exploring emotion. Refer to SIC Clinicians Reference Guide for more scripted language on common difficult responses (Eg. tears, anger, denial). March 26, 2020</i></p>	

# SERIOUS ILLNESS CONVERSATION GUIDE

## A CONVERSATION TOOL FOR CLINICIANS

### Adaptation for COVID-19

Cont'd

CONVERSATION FLOW	GUIDED SCRIPT
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#### 4. Explore key topics

- Meaning
- Fears and worries
- Sources of strength
- Family/People that matter
- Best care

"What is **most important** to you right now? What means the most to you, and gives your life **meaning**?"  
 "What are your biggest **fears and worries** about the future and your health?"  
 "What gives you **strength** as you think about the future?"  
 "How much does your **family/people that matter to you** know about your priorities and wishes?"  
 "Is there anything else that we need to know about you so that we can give you the **best care possible**?"

*Transition conversation to Step 5. Utilize paraphrasing and demonstrate empathy to let them know they've been heard.*

#### 5. Reassurance

"We want you to know that **our priority is to ensure that you are cared for and comfortable** if you become sicker. Regardless of the medical treatments that you get or do not get, your health care team will always provide treatments to help make you feel better. So it is important to let us know if you get a new cough, fever, shortness of breath or other signs that your health is changing. We will continue to support you as best we can to get the right help for you."

*Transition conversation to Step 6. Utilize paraphrasing and demonstrate empathy to let them know they've been heard.*

#### 6. Close the conversation

- Summarize what you've heard
- Make a recommendation within your scope of practice
- Check in with patient
- Affirm commitment

*\*Refer to Serious Illness Clinician Reference Guide for additional help with recommendations (page 18)\**

"I've heard you say that \_\_\_\_\_ is really important to you. Keeping that in mind, and what we know about COVID-19 and your current health, I **recommend\*** that we....

Focus: <b>Wellbeing</b>	"Talk again in a few days, to reassess where you are at."
Focus: <b>Illness</b>	"Talk with your primary care providers." "Make plans for care at home."
Focus: <b>Support System</b>	"Talk to your family/those that matter to you/including your Substitute Decision Makers."
Focus: <b>Help</b>	"Get you more information about risks and benefits regarding specific critical care treatments (e.g. restarting your heart or using a breathing machine)."

"How does this seem to you?"  
 "I know this is a scary time for all of us. We will do everything we can to help you through this."

**7. Document your conversation on the ACP Record and fax if non-acute setting. Communicate with primary care providers. Store in Greensleeve if paper charts are used in your setting.**

**8. Communicate with key clinicians.**

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## Symptom Management for COVID-19 (Adapted from Hendin et al)<sup>18</sup>

### Non-pharmacological management

- Recognize that nursing assessments of patients dying of highly transmissible acute respiratory infections are intensive, time consuming, and require a high degree of cognitive load. This will likely require a lower patient to nurse ratio and/or frequent relief of nursing duties.
- Review all medications and discontinue those not contributing to patient comfort.
- Discontinue devices not necessary for comfort or medication administration (i.e. monitors, nasogastric tubes, additional intravenous lines).
- Discontinue or minimize intravenous fluids and enteral feeding. If the decision is made to continue enteral feeding or intravenous fluids, monitor closely for complications including aspiration and pulmonary or peripheral edema.<sup>17</sup>

### Pharmacologic symptom management

**Avoid the use of the following as they may generate aerosolized virus particles and infect healthcare workers and family members.**<sup>19,20</sup>

- Fan
- High-flow oxygen
- Continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP)
- All nebulized treatments (bronchodilators, epinephrine, saline solutions etc)

### Basic symptom management at end of life<sup>18</sup>

#### Airway Secretions:

- Glycopyrrolate 0.4 mg subcut/IV q4h prn OR
- Scopolamine 0.6 mg subcut/IV q4h prn

#### Agitation/Delirium:

- Haloperidol 0.5-1mg subcut/IV q2h prn
- If severe add Midazolam 0.5-1mg subcut/IV q30 min prn
- If severe add Methotrimeprazine 12.5 – 25 mg subcut q4h prn

#### Pain:

If opioid naïve

- Morphine 2.5 – 5 mg subcut/IV q30 min prn OR
- Hydromorphone 0.5-1mg subcut/IV q30 min prn

If opioid tolerant, refer to opioid equianalgesic conversion tables for equivalent subcut/IV dosing

#### Dyspnea:

If opioid naïve, low dose morphine (50-75% of dose used for pain relief) is the medication of choice

- Morphine 1-2.5 mg subcut/IV q30 min prn OR
- Hydromorphone 0.25-0.5 mg subcut/IV q30 min prn OR
- Fentanyl 12.5 – 50 micrograms subcut/IV q15min prn

If opioid tolerant, give breakthrough doses to effect (breakthrough dose calculated as 10% of the total daily dose in 24 hours)

- If severe add Midazolam 0.5-1 mg subcut/IV q30 min prn
- For severe respiratory distress, consideration can be given to ketamine (1-2 mg/kg IV or 4 mg/Kg IM) as a temporizing measure until the above medications can be titrated to effect.

**Nausea/Vomiting:**

- Haloperidol 0.5-1mg subcut/IV q4h prn OR
- Ondansetron 4mg subcut/IV q6h prn

**Fever:**

- Acetaminophen 650 mg po/pr q4h prn

**A Chart/Poster Version of a Simplified Symptom Management Guideline is Below.**

- It has been specifically created for use in Manitoba
  - It is based on adaptations of similar guidelines from the University of British Columbia,<sup>21</sup> McMaster University<sup>22</sup>, and from the publication by Hendin et al.<sup>18</sup>

## MANAGING DYSPNEA IN PROGRESSIVE COVID-19 RESPIRATORY FAILURE RECEIVING END-OF-LIFE SUPPORTIVE CARE OUTSIDE THE INTENSIVE CARE UNIT

### FUNDAMENTAL CONCEPTS:

- PROGRESSIVE RESPIRATORY FAILURE IS A MEDICAL EMERGENCY.
- OPIOIDS RELIEVE RESPIRATORY DISTRESS, TREAT PAIN AND COUGH.
- DOSES ARE INDIVIDUALIZED TO TREAT SYMPTOMS, WITHIN ACCEPTABLE ADVERSE EFFECTS.
- RAPIDLY EVOLVING SYMPTOMS REQUIRE TITRATING SHORT-ACTING FORMULATIONS.
- OPIOIDS DO NOT HASTEN DEATH WHEN GIVEN PROPORTIONATE TO THE DEGREE OF DISTRESS.
- ASSOCIATED ANXIETY MAY BENEFIT FROM THE ADDITION OF BENZODIAZEPINES; PERSISTENT DELIRIUM MAY REQUIRE SEDATION.
- END-STAGE RESPIRATORY SECRETIONS ARE MOSTLY ASYMPTOMATIC FOR THE DYING PERSON.

**Discuss and Document  
Goals of Care  
and ACP status**

### Perform and Document Dyspnea Assessment:

Patient Report of Dyspnea  
Rating on Numeric Rating Scale (0-10)  
Clinical Assessment (RR, accessory muscle use, presence of restlessness or agitation)

### Doses for Opioid Naïve Patients

#### MORPHINE

- Start with 2.5 - 5mg PO or 1-2.5mg subcut/IV q4hrs PLUS 2.5-5mg PO or 1-2mg subcut/IV q1hr PRN for dyspnea

*Reduce dose (by half) in frail/elderly patients and those with severe heart, lung, or neurological diseases.*

*May also dose q6h instead of q4hrs*

*Avoid morphine if moderate/severe renal impairment*

**If using 4 or more PRNs in 24hrs, re-evaluate and consider titrating up.**

#### HYDROMORPHONE

- Start with 0.5- 1mg PO or 0.5mg subcut/IV q4hrs PLUS 0.5-1mg PO or 0.5mg subcut/IV q1hr PRN for dyspnea

*Reduce dose (by half) in frail/elderly patients and those with severe heart, lung or neurological diseases.*

*May also dose q6h instead of q4hrs.*

**If using 4 or more PRNs in 24hrs, re-evaluate and consider titrating up.**

#### For patients already on an opioid

- increase the dose by 25%.
- Adjust the breakthrough dose to 10% of daily dose.

### AVOID

Fans

High flow O2 (optiflow)

CPAP or BiPAP

Nebulized treatments

Deep suctioning

**(may aerosolize virus)**

**If starting opioid dose not effective and still dyspneic: TITRATE**

Increase regularly scheduled and prn doses by 50%. Monitor. Rate of titration depends on patient tolerance (e.g. somnolence) and how severe the symptoms.

**For severe and persistent dyspnea despite titration, add in Midazolam or Methotrimeprazine and/or call Palliative Care Team for advice**

### Medications for Associated Symptoms

#### Anxiety:

#### **LORAZEPAM**

0.5 - 2 mg SL q1h PRN  
Review doses used in 24 hours and consider q4-12h regular dosing

#### Severe anxiety / dyspnea:

#### **MIDAZOLAM**

1 - 4 mg subcut q30min PRN  
Review doses used in 12 hours and consider q4h scheduled dosing or continuous infusion

**MAY REQUIRE MUCH MORE**

#### Agitation / Restlessness:

#### **HALOPERIDOL**

0.5-1 mg subcut/IV q2h prn

#### **METHOTRIMEPRAZINE**

2.5 - 25 mg PO / subcut q4h PRN  
(more sedating)  
Consider q4h scheduled dosing

**MIDAZOLAM** (as above)

**THESE RECOMMENDATIONS  
ARE TO BE USED WITH GOOD  
CLINICAL JUDGEMENT**

“LOGO” (if approved)

Adapted From:

UBC End of Life Symptom Management. [https://med-fom-fpjt\\_sites.olt.ubc.ca/files/2020/03/End-of-Life-Symptom-Management-COVID-19.pdf](https://med-fom-fpjt_sites.olt.ubc.ca/files/2020/03/End-of-Life-Symptom-Management-COVID-19.pdf)

McMaster Protocol: Management of Dyspnea for Patients with COVID-19.

<https://fhs.mcmaster.ca/palliativecare/documents/McMasterDyspneaProtocolCOVIDHamilton31March2020.pdf>

**Consider palliative care consultation for:**

- Symptoms unresponsive to basic management protocol
- Symptoms not included on the basic management protocol
- Patients on pre-existing high dose opioids
- If medication resources are scarce and medication substitutions are required
- If alternate routes of medication are required

**Conclusion**

The palliation of patients with COVID-19 is inherently stressful due to the rapid changes in patient status, reallocation of health care resources, ever evolving clinical care guidelines, and the constant risk of harm to health care providers. As the role of providing end of life care for COVID-19 patients will likely involve many different health care providers, we hope that this document provides a basic framework for approaching care. By working together as a team, we can deliver compassionate communication and basic symptom management, even in the face of a pandemic.

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