

COVID-19 ACP Toolkit: Write your Advance Directive during the COVID-19 pandemic

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Advance Care Planning is important for all adults, no matter your age or state of health. The COVID-19 pandemic heightens the need and the urgency with which we should all complete our own Advance Care Plan.**

The onset of symptoms through to critical illness (requiring sedation and being put on a ventilator) can happen in just a few hours¹. This has been named “Sudden Acute Respiratory Syndrome Coronavirus 2,” or SARS-CoV-2². If this outbreak continues to develop, there may not be time to have discussions with your loved ones about your preferences for healthcare.

Have these vital discussions now, prior to the possibility of contracting an illness. Your loved ones and decision makers need to know your wishes in order to assertively speak for you.

During this pandemic, if you do not have anyone who healthcare professionals can readily contact to act as your Substitute Decision Maker, your Advance Directive should be as clear and detailed as possible.

During the COVID-19 pandemic, Advance Care Planning should be a *critical* call to action for³:

- Those over 50 years of age. The older you are, the more important this is.
- Those who have multiple medical issues (comorbidities), especially:
 - Heart disease of any type (including high blood pressure)
 - Chronic Lung Disease
 - Diabetes
 - Those who are immunocompromised for any reason, including taking medications and systemic therapies for any disease, including cancer.

¹ Characteristics and Outcomes of 21 Critically Ill Patients with COVID-19 in Washington State: JAMA Network, March 19, 2020: <https://bit.ly/2xbnrB9>

² Pandemic palliative care: beyond ventilators and saving lives: CMAJ; March 31, 2020: cmaj.ca/content/early/2020/03/31/cmaj.200465

³ Read DWDC's blog post on the importance of having end-of life conversations due to COVID-19: https://www.dyingwithdignity.ca/acp_and_covid19

- Pre-existing mental health issues such as depression or anxiety, which can worsen, especially with social isolation or the need to be a caregiver.

What is an Advance Directive?

An “Advance Directive” is the standardized name for the document in which you record your preferences for future healthcare. *The name of this document is different in every province. We have put the name of each province’s Directive and, legal requirements, at the end of this document.*

An Advance Directive is only put into place *when you are not capable of speaking for yourself.*

The important first step: Look deeply at your Values and Beliefs

If you were to acquire and survive this infection, what will you want your life to look like as you recover? There is a probability that your lung function⁴ will be compromised for a long time and, possibly, permanently. It is important to think about this – and it would be wise to discuss this with your loved ones and future decision makers now so they are able to relay this to your healthcare team.

What do you value? Do you value your independence and quality of life above all else? Or, would you give anything for time with your family, even if that meant limitations in what you are able to do?

How do you feel about quality of life versus quantity? Some of us would pick *quality* of life over *living a long time*. But many loved ones would pick more time with us. With this kind of disparity in goals, it is important to talk to those who will be making decisions for you and let them know what *you* want your life – or your death – to look like.

This may help your loved ones to say on your behalf, when you can’t speak for yourself, “Mom would want everything done...” or, “Dad, would not want to live like this...”

Where would you want to spend your last hours or days of life? We all have a picture of how we will spend our last days – and for most of us, it is not in the ICU, on a ventilator without loved ones at our side (due to isolation precautions). But, for those who become seriously ill because of COVID-19, this is a high probability.

Do you want spiritual ceremonies to be performed before/after your death?

What are the cultural beliefs that are important to you?

⁴ Here’s the Damage Coronavirus (COVID-19) Can Do to Your Lungs: Cleveland Clinic Health Essentials, March 20, 2020: <https://health.clevelandclinic.org/heres-the-damage-coronavirus-covid-19-can-do-to-your-lungs/>

Second step: Talk to your loved ones and those who will be speaking for you

These conversations are not easy, but if you want your future wishes for care to be known, you need to talk to your loved ones. Not only will this ensure that they know your preferences for care, but it can lead to more in-depth conversations with your loved ones about what is important to you.

Being simple, direct, and specific allows others to really hear what you are saying. Being honest and yourself is the best gift you can give to those who care for you most.

A note about your Substitute Decision Maker(s): This person should be readily available to speak to healthcare professionals by phone or in person. It should be a role they are ready and willing to take on. They should be able to make tough decisions in a time of crisis. They are also mandated by law to make the decision you would make if you were capable (even if that is different from their own).

Third step: Write your Directive

A few key terms in understanding your healthcare options:

CPR means Cardio-Pulmonary Resuscitation: “Cardio” means heart; “Pulmonary” means lungs; “Resuscitation” means to try and restart a person’s heartbeat and breathing when they stop. CPR is the act of manual, *aggressive*, compressions on your chest. “No CPR” is the same as “Do Not Resuscitate.” *In Alberta, No CPR is defined as “No Chest Compressions.”*

Defibrillation is a series of electrical shocks on the chest to reset the heart’s rhythm when someone has a lethal (life-ending) heart rhythm or cardiac arrest-

Dialysis is a machine that filters waste from your blood, which is a function normally performed by your kidneys. Often our kidneys take a “hit” and go into shock in an acute medical event, especially after a heart attack⁵, cardiac arrest, or major surgery. Dialysis can take over while the kidneys rest and recover, and in some instances, may only be needed over the short term. However, if you already have some kidney failure before a serious health event, your kidneys will take a further assault and may not recover. Ongoing dialysis risks versus benefits should be discussed with you and/or your Substitute Decision Makers.

Intensive Care and Critical Care Units (ICU and CCU): The names of the units are often used interchangeably. The units have more nurses and doctors per patient, and there is monitoring and life-support equipment and treatments including ventilators and dialysis.

⁵ The heart-kidney link: Heart Matters: <https://www.bhf.org.uk/information-support/heart-matters-magazine/medical/kidney-heart-link>

Respiratory: Non-invasive respiratory support is providing breathing and oxygen support for acute respiratory failure using a mask or similar device without a tube being put down the throat or via a tracheostomy⁶. This is usually provided by CPAP⁷ (Continuous Positive Airway Pressure) or BiPAP⁸ (Bilevel Positive Airway Pressure). **Note: Current guidelines for COVID-19 are that CPAP and BiPAP are not recommended for use, as they increase the risk to healthcare staff by the aerosolized virus.**

Ventilator is a machine that provides breathing support and oxygen through a tube down the throat via a tube in the mouth or a tracheostomy (surgical incision at the base of the throat). It might be used short-term during or after surgery, but it might also be used long-term for the rest of the person's life. Benefits versus risks should be discussed with the adult or Substitute Decision Makers based on the patient's values and beliefs.

Ventilation and COVID-19: Patients with COVID-19 are at risk of developing 'Sudden Acute Respiratory Syndrome Coronavirus 2' or SARS-CoV-2, respiratory failure and critically low oxygen levels which affects all organs. Best practice currently is to provide respiratory support with high flow oxygen. Like all procedures, benefits should outweigh the risks.

Think about the level of care you would want to receive

We have broken Levels of Care into five options, from most intensive to least intensive. *The focus at each level is on your values and beliefs – use this as a guide when talking to your loved ones and substitute decision makers. You can find the breakdown below for each of the five Levels of Care.*

1. Highest level of care: Includes all resuscitation, including CPR (chest compressions) and ventilator.
2. Intensive care *without* CPR, but including all other resuscitation, including a ventilator.
3. Conservative medical treatment but no resuscitation: No CPR (chest compressions), and no ventilator.
4. Symptom Management: Approaching End-of-Life. Symptom management and a focus on symptom control in place (home or residential care facility).
5. Symptom Management: End of Life. Stop feeding and drinking. Symptom management and a focus on symptom control, regardless of location.

⁶ Non-invasive ventilation in acute respiratory failure: <https://thorax.bmj.com/content/57/3/192>

⁷ Continuous Positive Airway Pressure (CPAP): Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/sleep-apnea/multimedia/continuous-positive-airway-pressure-cpap/img-20007977>

⁸ What is BiPAP?: Johns Hopkins Medicine: <https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/bipap>

1. Highest level of care including CPR (chest compressions)

This Directive is for those who are relatively healthy and want full resuscitation. Everything will be done to save your life. It states your values and beliefs and what you would (and would not) want your life to look like if you had unexpected serious injury or illness and could not speak for yourself.

Perform all resuscitation including CPR:

Example of Advance Directive:

I understand that all medical interventions including defibrillation, being on a ventilator, and being in a critical care unit will be provided.

Wherever possible, discuss risks versus benefits of ongoing resuscitation measures and ventilation, and ongoing therapy or surgeries with my Substitute Decision Makers and loved ones, and continue or discontinue care, based on my values and beliefs.

My Values and Beliefs:

2. Highest level of care without CPR (chest compressions)

This Directive is for those who may want the option of admission to ICU or CCU and want or need all medical care, including being on a ventilator – *but who do not want CPR (chest compressions)*. You may still want or need extra vigilance and care after a serious injury, illness, or surgery. It states your values and beliefs and what you would and would not want your life to look like if you could not speak for yourself.

Do not perform CPR but allow other forms of resuscitation and transfer to critical care.

Example of Advance Directive:

I understand the goal is to extend life for reversible conditions. Wherever possible, thorough, compassionate discussions with my Substitute Decision Makers should take place prior to making decisions so that they understand the risks versus benefits of all options. Continue or discontinue care, based on my values and beliefs.

My Values and Beliefs:

3. Medical Care without transfer to critical care

This Directive is for those who have significant health issues or frailty. You have discussed your values, beliefs and future preferences for healthcare with your loved ones and Substitute Decision Makers and are confident they will make the best decisions for you.

Note: Because this is 'conservative treatment', it does not include use of a ventilator but does include the option for non-invasive respiratory support such as CPAP or BiPAP (see glossary, above.)

Do not perform CPR (chest compressions) or any resuscitation: Symptom Management & Transport to Hospital for higher level of care.

Example of Directive:

I understand the goal is conservative management of medical conditions with specific short-term symptom-directed care to maintain my current level of function. Wherever possible, discuss risks versus benefits of any treatments or surgeries with my Substitute Decision Makers, and continue or discontinue care, based on values and beliefs.

My Values and Beliefs:

4. Approaching or at End-of-Life

This Directive is for those who have increasing health issues or frailty who are nearing the end of life. This is often the appropriate level for those in residential care or receiving palliative care. The goal is conservative management of medical conditions with specific short-term, symptom directed treatment. It may allow medications, such as oral antibiotics, to be given.

Do not perform CPR (chest compressions) or any resuscitation: Symptom Management & Supportive Care only.

Example of Directive:

I understand the goal is conservative management of medical conditions with specific short-term, symptom directed, treatment. Allow medications, such as oral antibiotics, to be given if these will improve symptoms. Wherever possible, discuss risks versus benefits of any treatments or surgeries with my Substitute Decision Makers, based on values and beliefs.

My Values and Beliefs:

5. End-of-Life

This Directive is for those who are at the natural end of life or who have a life-limiting disease and no longer want treatment but want to maximize comfort and symptom control at the end of life.

Do not perform CPR (chest compressions) or resuscitation: Symptom Management Only.

Example of Directive:

I understand the goal of this level of care is to make me comfortable. I am at the natural end of life or I have a life-limiting disease and no longer want disease-modifying treatment but want to maximize comfort and symptom control at the end of my life.

My Values and Beliefs:

Format for Advance Directives:

(See additional requirements for your province below)

Name of the Directive as per your province (see below)

Your full name

Date of Birth

Health Number

Address

Consider adding a list of your Substitute Decision Makers (legal document by province listed below) and their contact information.

That you revoke any previous Directives.

The content of your Directive.

Your signature

Your printed name

The date

Signature of your witnesses (number required, listed below)

Printed name of witnesses

Phone number and addresses recommended.

Advance Directive General Requirements:

- The term “Substitute Decision Makers” has become the Canada/North American-wide name for the selected person, either informally or informally. Every province has a different term for formal substitute decision makers, so we will use the term Substitute Decision Makers for clarity.
- Directives are only put into place when you are incapable of making your own health care decisions.
- With your permission, another person can sign on your behalf and must sign in front of witness(es).
- Witnesses, *generally*, can't be:
 - A paid caregiver, the legally named Substitute Decision Maker (SDM) or their spouse, or someone who will be a beneficiary. (See Dying with Dignity Canada province-specific toolkits:
https://www.dyingwithdignity.ca/download_your_advance_care_planning_kit)
- Your Substitute Decision Maker should attempt to check with you prior to making any decisions about your health care.

- Your Substitute Decision Maker cannot:
 - Make decisions prohibited by law
 - Ask for Medical Assistance in Dying on the adult's behalf
 - Delegate their role to another person

This list may vary depending on your location. Please review your provincial legislation or discuss any specific concerns with an estate or elder lawyer.

- The Hierarchy of Decision Makers is referenced if no Substitute Decision Maker (SDM) is named in a legal document or on your Directive (See Dying with Dignity Canada province-specific toolkits:

https://www.dyingwithdignity.ca/download_your_advance_care_planning_kit)

***A special note about Advance Directives and “Power of Attorney for Personal Care (POAPC)” in Ontario:**

In Ontario, an Advance Directive (AD) is not a legal document since there is no reference to AD in the health care legislation. This means that if you choose to write your preferences for future care in a document they will be treated as wishes but will not necessarily be followed exactly. In Ontario, health care professionals must get consent from the person or their SDM at the time of treatment. Your wishes, written or spoken in advance, are not consent. Any document with your future wishes for care is meant to advise your SDM (POAPC) and health professionals in making decisions on your behalf and it must be weighed with other factors. We advise that you write an AD to communicate your wishes clearly, but that you also understand that it is not consent nor a guarantee – there are many factors that weigh in a healthcare decision that may lead to different outcomes in certain situations.

Table: Advance Directive and Substitute Decision Maker Forms and Requirements

	Age Directive can be put in place	What the Directive is called	Directive witness requirements	Name of the formal/legal Substitute Decision Maker (SDM)	Name of formal/legal SDM Document
British Columbia	19 & capable	Advance Directive	Date, sign, TWO witnesses.	Representative	Representation Agreement 7 or 9
Alberta	18 & capable	Personal Directive	Date, sign, ONE witness.	Agent	As named in Personal Directive
Saskatchewan	16 & capable	Health Care Directive	Date, sign, ONE witness.	Proxy	As named on Health Care Directive
Manitoba	16 & capable	Health Care Directive	Date, sign and ONE witness (not required but recommended). (Government Health Care Directive form, does not need to be witnessed – See below)	Proxy	As named in Health Care Directive – Government form.
Ontario	16 & capable & available (either electronically or in person), and willing to act as SDM	Power of Attorney for Personal Care	Date, sign, TWO witnesses.	Attorneys	Named in Power of Attorney for Personal Care. In long-term care, create a 'Plan of Care'
New Brunswick	19 & capable.	Advance Health Directive	Date, sign, ONE witness.	Advance Health Directive = Proxy; Power of Attorney = Donator	Power of Attorney for Personal Care
Newfoundland/Labrador	16 & capable.	Advance Health Directive	Date, sign, TWO witnesses.	Substitute Decision Maker	As named in Advance Health Care Directive

Nova Scotia	19 & capable & willing to make decisions.	Personal Directive	Date, sign, ONE witness.	Delegate	As named in Personal Directive
Prince Edward Island	16 & capable & available.	Health Care Directive	Date, sign, ONE witness.	Proxy OR Substitute Decision Maker	As named in Health Care Directive
NW Territories	19 & understand the nature & effect of Personal Directive.	Personal Directive	Date, sign, ONE witness.	Agent	As named in Personal Directive
Yukon	16 & capable.	Directive	Date, sign, TWO witnesses over the age of 19.	Proxy OR Substitute Decision Maker	As named in Directive

Advance Care Planning & Conversations Resources:

Frailty: Interprofessional Comprehensive Geriatric Assessment Toolkit: <https://cgatoolkit.ca/>

LGBT End of Life Conversations (Simon Fraser Univ):

<https://www.sfu.ca/lgbteol.html>

Planned Lifetime Advocacy Network (support for people with disabilities):

<https://plan.ca/>

Speak Up: Advance Care Planning in Canada

<http://www.advancecareplanning.ca/>

Willow End of Life: Love Letters and Heart Wills

<https://willoweol.com/about/>

American conversation resources:

FIVE Wishes Conversation Guide:

<https://fivewishes.org/shop/order/product/the-conversation-guide-for-individuals-families>

The Conversation Project:

<https://theconversationproject.org/>

The Stanford Letter Project

<https://med.stanford.edu/letter/what-matters-letter.html>

Reading:

A Good Death, Sandra Martin

Being Mortal, Atul Gawande

Extreme Measures, Dr. Jessica Nutik Zitter M.D.

Lap of Honour, Gabby Eirew & Dr. Pippa Hawley

Life after the Diagnosis: Expert Advice on Living Well with Serious Illness for Patients and Caregivers

Talking About Death Won't Kill You: The essential guide to end-of-life conversations, Dr. Kathy Kortess-Miller

That Good Night, Dr. Sunita Puri
When Breath Becomes Air, Paul Kalanithi

For children:

All of these books (and more) can be found at <https://www.bookdepository.com/>

I Miss You: A first look at death, by Pat Thompson
The Memory Tree, by Britta Teckentrup
The Invisible String, by Patrice Karst
Always and Forever, by Alan Durant

*** Please note that if there is a surge of COVID-19 cases that require critical care, the clinical triage protocol may change and limit the treatment choices available, which could impact health care providers' ability to follow your Advance Directive.*