## Advance Care Planning
## Voicing your wishes in uncertain times

***Advance Care Planning is important for every adult but during the COVID-19 pandemic, it should be a critical call to action for many.***

The *Health Care (Consent) and Facilities (Admission) Act* (HCCFA), the *Representation Agreement Act, and The Canadian Charter of Rights and Freedoms* gives capable adults who are aged 18 or older the right to:

- be fully informed of all treatment options;
- have your Representative or Substitute Decision Maker recognized;
- have your Advance Directive followed;
- get a second opinion;
- have your pain and symptoms adequately managed;
- refuse treatment;
- end your own life; and
- choose a medically assisted death.

**Your Right to Refuse Treatment:**

Under the Canadian Charter of Rights and Freedoms **every capable adult has the right to:**

a) Consent to or refuse a treatment on any grounds, including moral or religious grounds, even if the refusal will result in death;
b) Select a form of available health care on any grounds, including moral or religious grounds;
c) Revoke consent at any time;
d) Expect that a decision to give, refuse or revoke consent will be respected; and
e) Be involved to the greatest degree possible in all case planning and decision making.

## Empowered Patients and Caregivers

- You are in charge of your body, mind and spirit.
- It is your life and your choice how to live it.
- You want to be treated as a person and not as a patient.
- You understand your rights as a patient, a substitute decision maker, and as a Representative.
- You consider what you would want for your life if you were to become seriously ill or injured and make your loved ones and decision makers aware of your wishes.

# Advance Care Planning

***It always seems too early…***
***Until it's too late.***

Because of the COVID-19 pandemic people are finally talking about a topic they normally want to avoid. *It's no longer too early.*

**Advance Care Planning (ACP)** is an umbrella term for conversations and documentation about your values, beliefs, and preferences for future care for a time when you can't make your own decisions.

**The vital first step…**

Think about your **Values & Beliefs, and preferences for future health care.**

Think about these things in context of where you are in your health journey.

Think about what's important in your life now, and in the future, in case of serious injury, illness, and end-of-life.

**Ongoing conversations**

Have frank conversations with your loved ones, Substitute Decision Makers, and healthcare team.

Starting these conversations may lead to deeper conversations over time.

**Important Health Documentation**

- Put together medical history and In Case of Emergency documentation.
- Choose your Substitute Decision Maker(s)
- Write a formal Advance Directive clearly stating your wishes for health care.

## Changing or Cancelling Your Advance Care Plan

When you are *capable*, you can change or cancel (revoke) any of your ACP documents at any time.

Note: if you a lawyer is writing your Advance Directive, ask that it is separate from other ACP documents, so you can change it as needed.

*If your Advance Directive is specifically in preparation for COVID-19, and it is different than it would be in other circumstances,* consider revoking, rewriting your Directive after this crisis has passed.

## STRATEGIES TO ASSIST IN COMPLETING YOUR ACP

**Prioritize: What needs to be done first?**

If something unexpected happened tomorrow (like COVID-19), what would you wish you would have done? What are your biggest risks? *Do this part of your ACP first!*

**Set up a buddy system:** set goals, dates, and mutual accountability.

**Put it into bite sized pieces.** Break ACP steps into realistic tasks. (Knowing that time is of the essence right now.)

**Reward yourself:** Something to mark that you have met this goal.

## CHOOSE YOUR SUBSTITUTE DECISION MAKER

"Substitute Decision Maker" (SDM) is the accepted world-wide term for the person who will make healthcare decisions for you when you are not capable of making decisions for yourself.

**Use caution when you are naming your "In Case of Emergency" person when being admitted to Emergency or Hospital. This person may be considered your Substitute Decision Maker.**

In BC, your SDM is formally and legally named on a *Representation Agreement (to be discussed below).*

### Temporary Substitute Decision Maker Hierarchy

If you are not able to make decisions on your own behalf and you have not assigned a Representative, a Temporary Substitute Decision Maker will be authorized to make decisions for you.  This hierarchy is in your province's health care legislation.

The TSDM is determined by their relationship to you and where they rank in this hierarchy:

1. Spouse (can be a common-law relationship)
2. Adult children
3. Parent
4. Sibling
5. Grandparent
6. Grandchild
7. Anyone else related by birth or adoption
8. Close friend (an adult with whom you have a long-term, close personal relationship involving frequent contact, but who does not receive compensation for providing your personal care or health care)
9. A person closely related by marriage

This TDSM hierarchy applies unless any of the people listed above have not been in contact with you for 12 months or more, and/or there is evidence of conflict between you.

## REPRESENTATION AGREEMENTS

**If memory issues are becoming apparent, it is imperative to make decisions regarding Representation and Enduring Power of Attorney documentation as soon as possible.**

**A few things to consider when choosing your Representative:**

- They can't be paid to care for you (except spouse or adult child)
- They must be a mentally capable adult *(age varies)*
- **They are readily available – even if by phone**
- **They are ready and willing to take on the role**
- **They will respect your religious or spiritual beliefs**
- ***They will carry out your wishes, even if they are different from their own and thus create difficult choices.***

Your **Representative** is often a close relative…
But you can also choose a close friend or neighbour.

**Your spouse may not be the best choice for Representative because:**

- They may just want to be your spouse in a time of crisis
- They may be physically or emotionally overwhelmed
- They may have their own health challenges
- They may not be able to or want to make difficult decisions.

**Talk with your Representative and loved ones. Share your values, beliefs, and preferences for future health care wishes. *Don't assume they will know what you would want.***

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.

### PREPARING YOUR REPRESENTATION AGREEMENT

NOTE: a lawyer is *not* required but consider seeking counsel for any complex situations.

- Do it yourself no cost: (See Resources, at the end of chapter)
  - Nidus.ca
  - Forms on Government of BC website
  - Forms on Public and Guardian and Trustee website
- For a fee:
  - Lawyers specializing in elder law or estate law

        - Elder law: Addresses legal issues and problems facing seniors, including age discrimination, elder abuse and exploitation, mental capacity and consent, medical and housing issues, guardianship, ethical and practical aspects of advising the older client (definition courtesy of the Canadian Bar Association, BC branch).
        - Estate law: Addresses legal issues related to the gathering of assets and debt after death. Can involve distributing the remaining assets of the estate.
    - Notaries public *who have experience with Advance Care Planning*.

  Note: If you seek legal counsel, look for a highly experienced estate or elder-law lawyer to draw up your documents.

**Who needs a copy of your RA?**

1. Your Representative and Alternate Representative. *Tell them their role, what the document is for, and ask them to keep it somewhere handy.*
2. Your Monitor (if you have an RA7).
3. Your doctor (should scan your original to your file).
4. Your bank (if you have an RA7).

## Types of Representation Agreements – RA7 and RA9

### Representative Agreement Section 7 (RA7)

An RA7 may be signed by someone who does not meet the traditional definition of capability. An adult may make an RA7 even if it is not clear whether the adult can make a contract. For example, adults with moderate to advanced mental illness or dementia may not be able to manage their day-to-day affairs but may still be able to name a person they trust to manage their health, personal, and can include routine management of financial affairs.

**The RA7 is authorized to assist you with:**

1. Health care: Help you make healthcare decisions or speak on your behalf when you are both capable and incapable.
2. Personal care: Collect your mail, water your plants, clean out your fridge, look after your pets, etc.
3. Financial assistance *(optional)*: Makes sure your rent and bills are paid; helps you make moving arrangements, etc.
    - It can be written if the adult has diminished capability but is still able to identify someone they trust as their decision maker.

- Allows you to name a person to make routine financial management decisions, personal care decisions, and some healthcare decisions. Does not allow the person to refuse life support or life-prolonging medical interventions for you.
- For an RA7 ALL (health, personal, and financial) you should appoint three people: Representative, Alternate Representative, and a Monitor. Your Alternate can only speak for you if the Representative cannot be reached (out-of-country or incapacitated). A Monitor is there to prevent abuse of power or position.
- The RA7 ALL is not appropriate for those who own property or have major investments.

Note: Many local financial institutions are not familiar with RA7s. Tell them to treat it as a Power of Attorney and send it to their head office for verification.

### Representative Agreement Section 9 (RA9)

***This is the most appropriate document for most adults.*** The RA9 does *not* allow for any financial management – an Enduring Power of Attorney should be considered if you wish to appoint someone to manage your financial affairs.

**The Representative 9 is authorized to assist you with:**

1. Health care: Your Representative helps you make healthcare decisions, including end-of-life care decisions, or speak on your behalf when you are unable.
2. Personal care: Collect your mail, water your plants, clean out your fridge, care for your pets, look after your dietary needs, etc. They can make decisions about future living arrangements, such as assisted living or long-term care.

Note: You may name one person for several roles (Representative, Enduring Power of Attorney, Executor, Guardian and/or Trustee) but separate documents are required. You may also name different people for different roles.

## DETERMINE YOUR VALUES AND BELIEFS

**Think about:**

- What makes life worth living?
- What can or can't be sacrificed or compromised?
- What needs to be completed before death?
- What is unacceptable to you: "I'd rather die in comfort than ____."
- Consider any special faith-based or cultural preferences.

- If you were to acquire and survive this infection, what will you want your life to look like as you recover?
- What do you value?
- How do you feel about quality of life versus quantity?
- Where would you want to spend your last hours or days of life?

## DETERMINE WHERE YOU ARE YOU IN YOUR HEALTH JOURNEY

Now, more than ever, consider your Values and Beliefs in a realistic context of where you are in your health journey.

***This will be discussed in detail below on pages 11 and 12.***

**If you become seriously ill *for any reason*, and require treatment, ask the following:**

- Benefits of treatments
- Risks and burdens of the treatments
- Short-term and long-term outcomes
- Alternative interventions and treatments
- Course of the disease if there is no intervention
- Comfort/palliative focused interventions.

Note: consider putting these questions somewhere that it is easily accessed for any time of serious illness or injury.

***Base all decisions on your values and beliefs.***

## TALK TO YOUR LOVED ONES AND REPRESENTATIVES

These conversations aren't easy.  Try to keep it simple, direct and specific.

*This may be the greatest gift you can give those you love the most.*

If it's just too tough to think of what to say…

Write a heart-felt letter and, if possible, read it out loud.

Start with statements that will ease their minds a bit:

"I read an article last week from a doctor saying that everyone should be having discussions about what they want if they were to get seriously ill.  I thought it would be a good idea to talk about that now…"

## ADVANCE DIRECTIVES

***Conversations with your loved ones and Representatives are the most valuable and important part of Advance Care Planning.***

During this pandemic, if you have not identified a Representative or Substitute Decision Maker, or they may not be immediately available to speak to a healthcare professional, **your Advance Directive should be as clear and detailed as possible.**

**On your Advance Directive, healthcare clinicians need to know:**

- Your name, date of birth, and Personal Health Number.
- Who is going to speak for you if you no longer have the capacity to speak for yourself?
- Specific medical treatments you do and do not want such as CPR, intubation and ventilation.
- Your Values and Beliefs.
- That it is signed, witnessed and dated.

**Representation Agreements take precedence over Advance Directives…**
**But they are meant to work together.**

We don't have crystal balls when writing our Advance Directives and we simply can't know what the best course of treatment in the future will be. Therefore, your conversations with your loved ones and Representatives about your values and beliefs are vital so they can make the best decisions for you in any given circumstance.

## WRITE YOUR ADVANCE DIRECTIVE

**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 where you are in your health journey and on your values and beliefs.

Use this as a guide when talking to your loved ones and Substitute Decision Makers and writing your Advance Directive.

*No matter the level of care you want to receive, add statements about your values and beliefs so your loved ones, Substitute Decision Makers and Health care teams, get to know you a little better and why you have made the decisions you have.*

Level Five

## Highest level of care: Perform all resuscitation including CPR*

*Cardiopulmonary Resuscitation

**This is for those who are relatively healthy and want full resuscitation.** ***Everything will be done to save your life.***

Cardiopulmonary Resuscitation includes chest compressions, intubation, ventilation, and defibrillation. If your heart is restarted, you *will* go to ICU and you will likely be on a ventilator.

Level Four

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

**This 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.

***Important note: Use of a ventilator is "Life Support".***

***Note: you can choose this level of care but you can also stipulate treatments you don't want done, such as a ventilator or dialysis.***

Level Three

## Medical Care without transfer to critical care: Do not perform CPR or any resuscitation. Symptom Management & and may involve transport to hospital for higher level of care.

**This is meant for those who have significant health issues or frailty.**

*(Hint: if you wanted 'No Heroics', this is likely what that would be interpreted as.)*

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 *(with possible restriction for COVID-19 positive patients).*

Level Two

## Approaching or at End-of-Life:

**Do not perform CPR or any resuscitation.**
**Symptom Management & Supportive Care only.**
**This is for those who have multiple health issues or frailty who are nearing the end of life.**

This is often the appropriate level for those in long term 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.

Level One

**End-of-Life: Do not perform CPR (chest compressions) or resuscitation.**
**Symptom Management Only.**
**This 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.

## A CHECKLIST FOR A COMPLETED ADVANCE CARE PLAN

**I have:**

- ☐ I've chosen my future Substitute Decision Makers
- ☐ Thought about my values and beliefs.
- ☐ Decided on my preferences for future health care.
- ☐ Discussed my values, beliefs and preferences for future health care with my Substitute Decision Maker(s).
- ☐ Completed my Advance Directive and have had it signed and witnessed.
- ☐ Completed or reviewed my Power of Attorney (POA) for finance and indicated where it can be found.
- ☐ Completed or reviewed my Will and indicated where it can be found.
- ☐ Provided any wishes about ceremonies, instructions and funeral arrangements for after your death.

***A few additional hints of things to think about:***

- Do you have someone else in your home that will need care? Clearly indicate that… and who First Responders should call.
- Plan for your pets and have those clearly indicated on your documents.
- Let someone know where all relevant account and computer passwords are!

**Put copies of relevant documents in a clear folder or binder and place these documents on or beside your fridge *(or put a clear note on your fridge where these documents can be easily found).***

**Give copies of important documents to your Substitute Decision Makers, your Enduring Power of Attorney, and your Executor.**

***There is a lot of information in this presentation. But it comes down to one massively important step…***

Talk to the people you love, and those who might be making decisions for you about your Values, your Beliefs, and your Preferences for future health care.

In order to have your choices met, you must clearly communicate them to your loved ones, Representatives, and healthcare teams.

## ADDITIONAL INFORMATION:

## In Case of Emergency (ICE)

**Prepare a detailed medical history and current medications.**

A free, fillable, and printable In Case of Emergency form can be found at:
http://patientpathways.ca/wp-content/uploads/PP_ICE_Form_2019.04.09.pdf

## A note about medical Levels of Care orders:

They are orders signed by a doctor or nurse practitioner (usually in hospital) after consulting with you or your Substitute Decision Maker about the level of resuscitation you would want to receive.

In BC they are called:
**MOST:** ***Medical Orders for Scope of Treatment***
Except for Providence Health, where they are called *Options for Care.*

Discussions and decisions for your Advance Directive are made *prior* to a crisis.
Medical orders are often written *during* a hospitalization and crisis.
**Your Advance Directive and medical orders should work hand-in-hand.**

## Notes about respiratory support 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.

**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 tracheostomy. This is usually provided by CPAP (Continuous Positive Airway Pressure) or BiPAP (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.*

**A 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.

**Current data is indicating that 40 to 50% of patients with COVID-19 are being successfully weaned from ventilators.**

However, ventilation can be required for several weeks, which can lead to serious complications from organ and muscle 'deconditioning' which can be fatal and will certainly result in long-term rehabilitation requirements.

There is data indicating that lung damage can be significant and permanent.

## ACP FINANCIAL PREPARATION

***Leave a legacy…***
***Not a mess!***

This is an opportunity to review and put in place your paperwork for ACP Financial Preparation and Estate Planning.

*Financial Planners, Notaries and Lawyers are still all working – although, like the rest of us – remotely via telephone or teleconference.*

**For any additional questions or concerns, please reach out to Connie at [ConnieJ@PatientPathways.ca](mailto:ConnieJ@PatientPathways.ca)**

**Buy Connie's book:**
***Advance Care Planning: Prepare for Serious Illness***
**By going to Self Counsel Press, Amazon, or Indigo Books**

**See the next page for more Resources…**

## Advance Care *Planning* & *Conversations*:

**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/

### US based resources:

**FIVE Wishes Conversation Guide:**
https://fivewishes.org/shop/order/product/the-conversation-guide-for-individuals-families

**The Conversation Project:**
https://fivewishes.org/shop/order/product/the-conversation-guide-for-individuals-families

**The Stanford Letter Project**
https://med.stanford.edu/letter/what-matters-letter.html

## Advance *Directives* & End of Life Considerations

### Reading:

**A Good Death**, Sandra Martin — ISBN: 9781443435963
**Being Mortal**, Atul Gawande — ISBN: 978-0-385-67700-4
**Extreme Measures**, Dr. Jessica Nutik Zitter M.D. — ISBN: 978-1101982556
**Lap of Honour**, Gabby Eirew & Dr. Pippa Hawley — ISBN: 9781775181101
**Life after the Diagnosis:** Expert Advice on Living Well with Serious Illness for Patients and Caregivers — ISBN: 978-0-7382-1938-7
**Talking About Death Won't Kill You: The essential guide to end-of-life conversations**, Dr. Kathy Kortes-Miller — ISBN: 978-1-77041-406-8

**That Good Night**, Dr. Sunita Puri — ISBN: 978-0735223318
**When Breath Becomes Air**, Paul Kalanithi — ISBN: 978-0-8129-8840-6

### For children:

*All of these books (and more) can be found at* https://www.bookdepository.com/I-Miss-You-First-Look-at-Death-Pat-Thomas/9780764117640

**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

### Viewing:

A lighthearted, entertaining and incredibly educational video:
***Dr. Seuss Does Advance Directives: A Tim Boon Poem*** | ZDoggMD.com:
https://www.youtube.com/watch?v=xy-JTh1Vo8o

An incredibly frank, and not for the squeamish, looks at the tough conversations in ICUs. Oscar winning documentary available on Netflix:
***Extremis:*** https://bit.ly/2MhBvj4

## Palliative and Hospice:

**BC Hospice and Palliative Care Association:**
https://bchpca.org/
**Canadian Hospice and Palliative Care Association:**
http://www.chpca.net/
**Paul Sugar Palliative Support Foundation:**
https://www.paulsugarfoundation.com/

## Financial Planning for Serious Illness, Injury and Incapacity

### Government Resources:

**Employment Insurance Sickness Benefits:**
https://www.canada.ca/en/services/benefits/ei/ei-sickness.html
**Employment Insurance Compassionate Care Benefits:**
https://www.cancer.ca/~/media/cancer.ca/AB/get%20involved/take%20action/FederalCompassinateCareBenefitProgarm-AB.pdf?la=en
**Canada Pension Plan Disability Plan:**
https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit.html

## Reading:

***We took a snapshot of the last year of people's lives and this is what we found*** – Dr. Anna Schneider – School of Health and Social Care: http://theamateursguide.com/we-took-a-snapshot-of-the-last-year-of-peoples-lives-heres-what-we-found/

***Early financial advice prevents worries at the end:*** https://www.financialstandard.com.au/news/early-financial-advice-prevents-worries-at-the-end-131121973?related=131120033