Time Out for Care Partners Webinar Series

Parkinson Society of BC

Advance Care Planning

For family caregivers and those they are caring for

Presented by

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Independent Healthcare Navigator & Patient Advocate

Patient Pathways

INDEPENDENT HEALTHCARE NAVIGATORS & ADVOCATES

Patient Pathways

Empowering patients and those who love them.

Patient Pathways

Advance Care Planning

Prepare for Serious Illness by Sharing Your Wishes for Future Health and Personal Care

Includes free access to downloadable kit

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Self-Counsel Press
HEALTHCARE

There are detailed indexes and resources in the book. Read what you can, what you need, when you need them.

And then, put the book in your *In Case of Emergency* folder and use it as your guide when you or your loved ones are in the healthcare system.

Patient Pathways

Serious and complex illness, injury, and life-ending diagnosis can and do happen to any one of any age.

Patient Pathways

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 Planning.

It always seems too early…

Until it’s too late.

Caregivers often neglect their own Advance Care Planning…

Are you looking after you?

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.

This is a vital topic for family caregivers who:

- **Are reluctant to bring up these conversations with those they care for…**
- **And don't think to do this important planning for themselves.**

Estate Planning

Financial Preparation

Values & Beliefs

Ongoing Discussions

Health Documents

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Advance Care Planning documentation is done in preparation *for a time*

when you are no longer capable

of making your own healthcare decisions.

During COVID-19 this is extremely relevant.

An important note for these uncertain times:

With COVID-19, the progression of the illness can be sudden, and even prior to ventilation, you may be so ill that you can't make decisions and will need to rely on others.

If you are on a ventilator, you will likely be deeply sedated and others will need to make decisions for you.

For yourself and for those you love and care for, the process is:

1. **Consider the Values and Beliefs – of your loved one, as well as your own.** *(70% of spouses do not fully understand values, beliefs, and preferences for care.)*

2. **Determine where you are in your health journey** *(a vital step assessment with COVID-19)*

3. ***Choose* your Substitute Decision Maker(s)**

4. **Talk with your Substitute Decision Maker(s) and loved ones**

5. **Document your wishes.**

STRATEGIES TO ASSIST IN COMPLETING ACP

Prioritize: What needs to be done first?

If something unexpected happened tomorrow (like COVID-19), what would you need to have done?

What are the biggest risks to you are the person you are caring for?

Do this part of your ACP first!

- **Set up a buddy system.**
- **Put it into bite sized pieces.**
- **Reward yourself.**

Changing or Cancelling Advance Care Planning Documents

When a person is *capable*, any ACP documents can be changed or cancelled (revoked) at any time.

Step One…

Think about

Values & Beliefs
& preferences for future health care.

Have these vital discussions now, prior to the possibility of serious illness.

Decision makers need to know the wishes of those you care for in order to assertively speak for them.

In this webinar, our focus on Values and Beliefs is a short exercise, focused on a time of crisis.

- What makes life worth living?
- What can or can’t be sacrificed or compromised?
- What needs to be completed before death?
- Consider any special faith-based or cultural preferences.

- What do you or your loved one value?
- How do you feel about quality of life versus quantity?
- Where would you/they want to spend the last hours or days of life? (Home, hospice, residential care.)

Step Two…

DETERMINE WHERE YOU ARE IN YOUR HEALTH JOURNEY

Consider Values and Beliefs in a realistic context of health and age.

(We'll go through this in Advance Directives.)

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

Step Three…

CHOOSE YOUR SUBSTITUTE DECISION MAKER

Just a quick overview…

"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.

If your loved one is not able to make decisions on you’re their own behalf and they have not assigned a SDM, a Temporary Substitute Decision Maker (TDSM) will be authorized to make decisions for them.

This is not always the person who is looking after them at home. If they want you to speak for them, strongly consider a Representation Agreement.

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

The TSDM 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.

In BC, a SDM is formally and legally named on a

Representation Agreement

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 a Representative

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

The Representative is often a close relative…

But they can also be a close friend or neighbour.

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.

PREPARING YOUR REPRESENTATION AGREEMENT

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

Do it yourself no cost:

- Nidus.ca
- Forms on Government of BC website
- Forms on Public Guardian and Trustee website

For a fee:

- Lawyers specializing in elder law or estate law.

Note: If you are going to a lawyer to draw up your documents, they often put all ACP documents together. Ask that they are separated.

This is especially important for the Representation Agreement and Advance Directive.

- In a time of health crisis, physicians will not take the time to read through a 20 page document.
- You need to be able to update the documents as your health and circumstances change.

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.

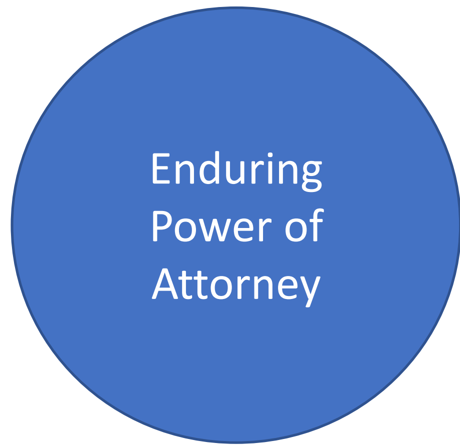
They may still be able to name a person they trust to manage their health, personal, and can include routine management of financial affairs (optional).

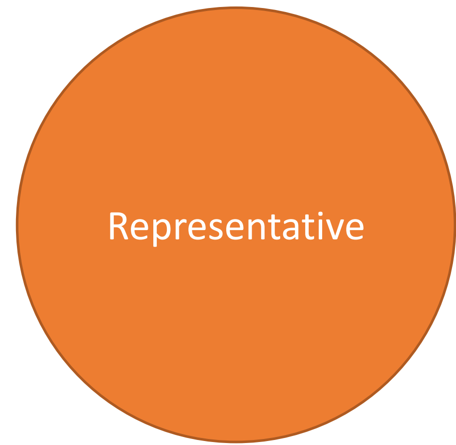
Representative Agreement Section 9 (RA9)

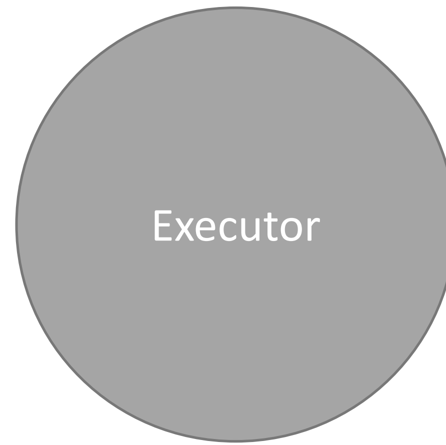
This is the most appropriate document for most adults. The RA9 does *not* allow for any financial management – an Enduring Power of Attorney should be considered if you wish to appoint someone to manage your financial affairs.

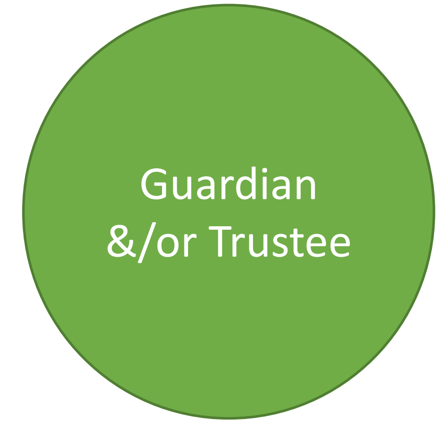
The Representative 9 is authorized to assist you with:

- **Health care:** Your Representative helps you make healthcare decisions, including end-of-life care decisions, or speak on your behalf when you are unable.
- **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 or more people for several roles but *separate documents are required*.

Step Four…

Talk with your Substitute Decision Maker(s) and loved ones.

Conversations with your loved ones and Substitute Decision Makers are the most valuable and important part of Advance Care Planning.

These conversations aren’t easy.

Try to keep it simple, direct and specific.

Ongoing conversations

Starting these conversations may lead to deeper conversations over time.

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 would want if they were to get seriously ill. I thought it would be a good idea to talk about that now…”

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

Document your Preferences for Future Care

Step Five…

Advance Directives

Every province has a different name and healthcare legislation stating your values, beliefs and preferences for future health care.

The universally recognized term is ‘Advance Directive’.

In BC it is called an ‘Advance Directive.’

When documents are called something else…

- Living Will
- Basic Advance Care Plan
- Personal Directive

…and if it is not signed, dated and witnessed by 2 people, it will be considered, but it is *not* legally enforceable documents. (As per the Health Care Consent Act.)

During this pandemic, if you have not identified a 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:

- 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.

Representative discussions and decisions take precedence over Advance Directives…

Unless you state otherwise in the document.

But Representatives are legally obligated to honour your wishes, or what they believe you would want, if you had been able to speak for yourself.

Who can write an Advance Directive?

You can. If it meets the legal requirements and is properly witnessed, it is valid.

Strongly consider discussing the most appropriate level of care with your physicians or nurse practitioner.

We have based the following examples of Advance Directives on medical levels of care which are similar across North America.

MOST

Medical Orders for Scope of Treatment

(Providence Health Authority orders are called Options for Care)

A note about ACP *medical* 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.

Discussions and decisions for your
Advance Directive are made *prior* to a crisis.

Medical orders are most often written *during* a hospitalization and crisis.

Your Advance Directive and medical orders should work hand-in-hand.

WRITE YOUR ADVANCE DIRECTIVE

THINK ABOUT THE LEVEL OF CARE YOU WOULD WANT TO RECEIVE

We have broken this 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 Representatives and writing your Advance Directive.

Level FIVE

Highest level of care:
Perform all resuscitation including CPR*

*Cardiopulmonary Resuscitation

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.

If you do *not* want to be resuscitated…

At home or in the community you *must* have a No CPR form signed by you and your doctor and have that form with you or have a Medical Alert* bracelet on.

This is for those who are relatively healthy and want full resuscitation.

Everything will be done to save your life.

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.

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.

Important note:

Use of a ventilator is “Life Support”

Level THREE

Medical Care *without* transfer to critical care: Do not perform CPR (chest compressions) 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.

Because this is 'conservative treatment', it does not include use of a ventilator *but can include the option for non-invasive respiratory support such as CPAP or BiPAP.*

Level TWO

Approaching or at End-of-Life:
Do not perform CPR (chest compressions) 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 residential care or receiving palliative care who are nearing end of life. 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 FIVE

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:

- ✓ 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.

Put copies of relevant documents in a clear folder, binder, or Green Sleeve and place these documents on or beside your fridge

(or put a clear note on your fridge indicating 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.

If your 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.

A few additional important notes…

In Case of Emergency

In order to get your information to First Responders, paramedics and Emergency Room physicians quickly and accurately, gather your medical history, medications and emergency contacts in one place.

Go to the Patient Pathways ICE form, online. It is a FREE, fillable, saveable, and printable form: http://patientpathways.ca/wp-content/uploads/PP_ICE_Form_2019.04.09.pdf

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.**
- **Make pre-arrangements for your pets and have those clearly indicated on your documents.**
- **Let someone know where all relevant account and computer passwords are!**

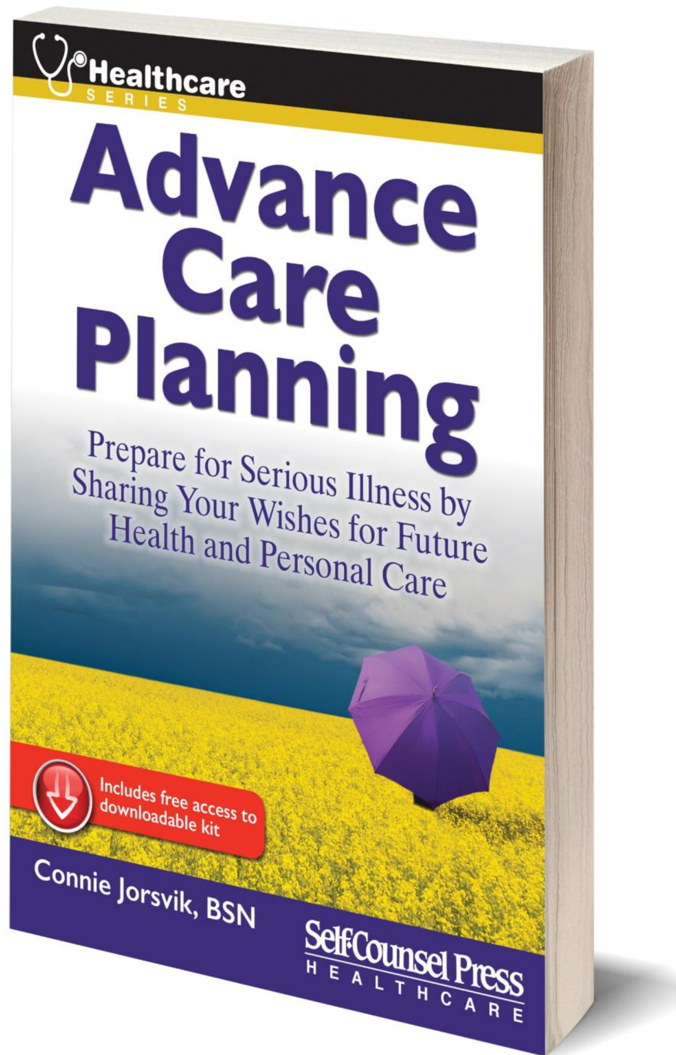
Leave a legacy…

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.

Questions



Where to Buy My Book

Self Counsel Press:

E-book: https://www.self-counsel.com/advance-care-planning-epub.html

Soft Cover: https://www.self-counsel.com/advance-care-planning.html

Can also be found by searching
"Advance Care Planning + Connie Jorsvik"
and available through Amazon, Google Books, and Indigo.

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We wish you health and happiness as we continue through these uncharted waters.

Thank you for being with us!