ADVANCE CARE PLANNING

A GUIDE FOR YOUR FUTURE HEALTH DECISIONS

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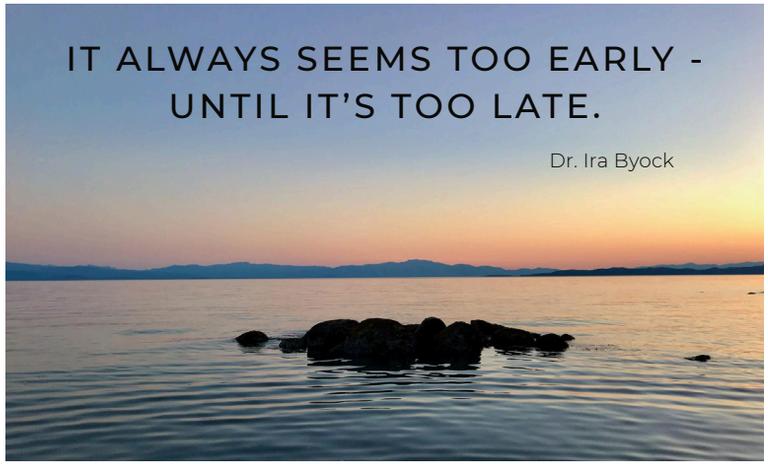


WHAT IS AN ADVANCE CARE PLAN AND WHY SHOULD YOU HAVE ONE?

Advance care planning (ACP) is a process of thinking, talking and making notes about what you would want to happen if there was a time when you were unable to speak for yourself. Putting a plan in place now gives you a say in your future health care and personal care decisions.

It is a process of sharing your values, beliefs and wishes to support informed health care and personal care decision-making. This gives you the best chance of getting care that's right for you. Have conversations with your loved ones and health care providers while you are healthy so they know your wishes.

LET YOUR FAMILY KNOW WHAT YOUR WISHES ARE IN CASE YOU EVER BECOME TO TOO ILL TO MAKE DECISIONS FOR YOURSELF.

None of us want to contemplate our frailty or our mortality, but doing so may be the kindest and most loving gift you can give your family and loved ones.
Even if you are perfectly healthy, it is important to establish a plan - illness or injury can happen no matter your age or health status.

ADVANCE CARE PLANNING STEPS

01

THINK

About what you would want if you are not able to speak for yourself.

02

LEARN

What your health care choices may be when you become ill.

03

DECIDE

Who you would want to speak for you if you were unable to speak for yourself.

04

TALK

With the people you care about, and who care about you, to let them know what your future wishes are.

05

DOCUMENT

Your advance care plan by reviewing and completing the Green Sleeve package.

IT IS NOT ABOUT HOW YOU WANT TO DIE BUT RATHER, ABOUT HOW YOU WANT TO LIVE.

If you had an accident and weren't expected to wake up, what would you want your family and your health care team to do?
Who would make decisions for you?

If you were diagnosed with an illness that could not be cured but could be managed for a period of time, **what would be important to you?**
What would you be willing to endure for the sake of more time?

If your loved one was injured and not able to speak for themselves, **would you know what care they want?**

THE PROCESS OF PLANNING CAN HELP YOU TO:

- Understand your medical options
- Explore your values and preferences
- Help those close to you understand what you want
- Prepare you, or those close to you, to make difficult decisions in a health crisis.

01

THINK

ABOUT YOUR WISHES FOR MEDICAL CARE

Reflecting on your personal values and beliefs, and their importance, helps you make decisions about what you want or do not want for your future care.

ASK YOURSELF:

What does quality of life mean to me?

What brings me joy and makes my life worth living?

What abilities are so crucial to my everyday life that I can't imagine living without them?

What would I be willing to give up for the potential of gaining more time?

What matters most to me?

What do I worry about most when it comes to my future health, or death?

Will my spiritual or religious beliefs have an impact on my future health care?

It is also possible you may find yourself having to make decisions for someone you love. **Do you know what is important to them?**

If you are healthy and have no underlying health conditions, you might think an advance care plan isn't relevant to you, but it is.

ILLNESS OR INJURY CAN STRIKE ANY OF US AT ANY TIME.

If organ donation is important to you, it needs to be documented. Register with ***www.transplant.bc.ca*** and make sure your family knows your wishes.

02

LEARN

ABOUT YOUR OPTIONS AND CHOICES

If you have chronic health conditions, it is useful to learn more by having an in-depth conversation with your healthcare practitioner. This is called a goals of care or advance care planning conversation.

GOALS OF CARE

This conversation provides an opportunity for you and your doctor to set your goals of care in the event of serious illness. You can learn more about your health trajectory and how it may affect your quality of life in the future, what treatment options there may be for you, and what the impact and side effects of those treatments may be.

You and your doctor will want to discuss your values and wishes to understand what is medically acceptable and appropriate for you. You may also want to discuss your wishes around personal care. For example:

- How will your needs change, and how much assistance are you prepared to accept?
- Will your family be able to support you at home? How manageable would that be for your family?
- How would you feel about going into the hospital, hospice, or long term care?
- What side effects of illness or treatments would be acceptable?
- As your health declines, what would you be willing to give up or change to gain more time?

A goals of care conversation puts your wishes into a clinical context and results in written medical orders for the level of intervention you are comfortable with. Your healthcare providers will always ask you first, but if you are unable to speak for yourself then the medical orders that resulted from your conversation will guide the people who have to decide for you.

When you book the appointment to talk to your doctor, let them know you want to talk about advance care planning. Prepare your questions ahead of time, and consider inviting your representative or a family member to come to the appointment with you.

Ask your doctor to complete a MOST form with you and give you a copy for your Green Sleeve.

MOST FORM

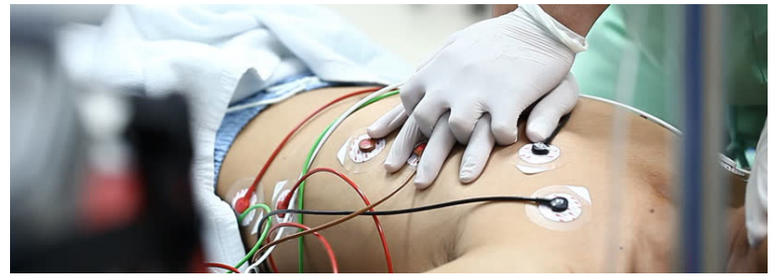
MOST stands for Medical Orders for Scope of Treatment, and is a doctor's order for treatment options used in hospitals, residential care and community settings. You may encounter a MOST when you're chronically ill or near end-of-life, and major health care decisions are looming. In the event of a critical health emergency a MOST form clarifies the level of critical care interventions you would want, including CPR or aggressive life support treatments in intensive care units.

A MOST form describes a scope of care from the full range of critical care interventions and preservation of life, to allowing a natural death, with pain and symptom management for comfort but no interventions.

Your MOST status can be changed at any time through conversations with your healthcare provider.

The decision to decline CPR can be recorded on either a NO CPR form or a MOST form. A NO CPR form only communicates to first responders and healthcare providers that the patient no longer wants to have CPR in the event of a respiratory or cardiac event whereas a MOST form provides emergency personnel with more information than does the NO CPR form.

For this reason the MOST form is becoming the preferred document to ensure that patients receive the level of care they want, or don't want, in a medical emergency.



Cardiopulmonary resuscitation (CPR)
Chest compressions or other direct means of restarting the heart is an emergency procedure that can be performed if your heart or lungs stop. Some people decide they don't want that. Declining CPR is not a decision to be made lightly. Talk to close family and friends and your doctor to see if it's the right option for you. The answer will depend on your unique circumstances.

For more information on Goals of Care Conversations, MOST forms and CPR, ***go to www.coasthospice.com/acp***

03

DECIDE

WHO WILL MAKE YOUR DECISIONS

- Who would make decisions for you if you were unable to speak for yourself?
- If you become incapable of giving informed consent to a health care treatment, someone will need to make the decision for you.
- The best option is to choose a representative ahead of time by completing a representation agreement.
- If you do not have a representation agreement in place, a temporary substitute decision maker will be chosen for you.

ASK YOURSELF:

Who knows me well and would be willing and able to take on the role?

Whom do I trust to make decisions that honour MY wishes and instructions?

Who is calm in a crisis and able to handle conflict?

Who is readily available?

TEMPORARY SUBSTITUTE DECISION MAKERS (TSDM)

BC law specifies the order in which your decision maker would be chosen. Your health care team would approach the following people in order to determine who is the first person eligible and available to make decisions on your behalf:

1. Your spouse (married, common-law - length of time living together doesn't matter)
2. A son or daughter (19 or older, birth order doesn't matter)
3. A parent (biological, adoptive or guardian)
4. A brother or sister (birth order doesn't matter)
5. A grandparent
6. A grandchild (birth order doesn't matter)
7. Anyone else related to you by birth or adoption
8. A close friend
9. A person immediately related to you by marriage (in-laws, step-parents, step-children, etc.)
10. Someone appointed by the Public Guardian Trustee

- **You may not change the order of the list.**
- **A person lower down on the list may only be chosen as your TSDM by your health care provider if all the people above them do not qualify or are not available.**

A TSDM MUST BE:

- 19 or older
- Be capable
- Have no dispute with you
- Have been in contact with you in the past year

REPRESENTATION AGREEMENTS

It is best to appoint your own representative by preparing a legal document called a representation agreement so that you choose who your representative will be.

You can talk to them in advance about your future wishes and, in doing so, you can have greater comfort in knowing that your advance wishes will be honoured or shared.

A representation agreement is designed to be used at a future time when you may be unable to make certain decisions for yourself. You can designate a specific representative (or more than one).

A lawyer or notary public can assist you in drafting a representation agreement or you can prepare it yourself using standard forms. It must be signed and witnessed.

Under BC law, there are two types of representation agreements.

AN ENHANCED REPRESENTATION AGREEMENT

This is also known as a Section 9 representation agreement and is the one that most legally capable people will complete.

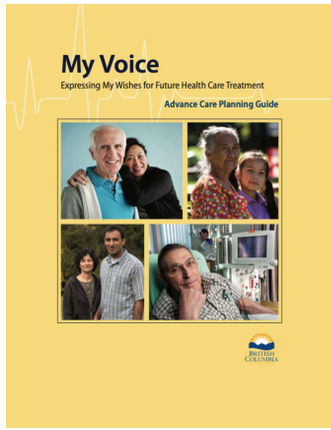
It permits your representative to make decisions regarding personal care and health care, including but not limited to end of life decisions and admission to certain care facilities. It does not allow the representative to make any financial or legal decisions, because a fully capable individual would be able to assign legal and financial representation in a power of attorney document.

A STANDARD REPRESENTATION AGREEMENT

Also known as a Section 7 representation agreement, this is the document that is most often used when someone already has cognitive impairment and/or a diminished capacity to make decisions. In this case health and personal care decisions are more limited but the representative may also make certain financial/legal decisions that are not part of an enhanced representation agreement.

You can find blank representation agreement forms on the Sunshine Coast Hospice website, or in the BC Government document:

My Voice: Expressing My Wishes for Future Health Care Treatment. (See Resources section at the back of this booklet.)



For more information on Temporary Substitute Decision Makers and the differences between Standard and Enhanced Representation Agreements,
go to www.peopleslawschool.ca
Planning for your Future: Health & Personal Care

04

TALK

ABOUT YOUR WISHES WITH THOSE WHO CARE ABOUT YOU

"We can't plan for everything. But we can talk about what is most important - in our life, and in our health care - with those who matter most. Talking with the important people in our life can bring us closer together. It helps us to create the foundation of a care plan that's right for us - a plan that will be available when the need arises."

- The Conversation Project

To get ready to have conversations with your loved ones, it can be helpful to write things down to help you organize your thoughts and plan your conversations about what matters most to you about your future health care to the end of your life. Think about where and when would be a good time to talk, and then just start!

TALK TO YOUR FAMILY AND FRIENDS

About your medical care wishes and choices.

TALK TO YOUR DESIGNATED REPRESENTATIVE OR SUBSTITUTE DECISION MAKER(S)

To ensure they can make your decisions (or make the decisions you would) when the time comes.

TALK TO YOUR DOCTOR(S)

About your medical options and what is important to you.

As a place to start, watch our film "Living with Dying" to learn from the experiences of other Sunshine Coast residents. A link to the film is available on our website.

The Conversation Project website is another great resource for getting the conversation started.
Go to www.theconversationproject.org

SOME SUGGESTIONS:

- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances change.
- Every attempt at the conversation is valuable. Keep trying.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

05

DOCUMENT

YOUR WISHES

- If you choose to document your wishes about your future medical care, write down your beliefs, values and wishes in an advance care plan.

  Another option is to use legal documents to document your personal wishes in your representation agreement, or by completing a legal advance directive to address specific treatments for certain medical situations.

  If you wish to include specific treatments to be administered or witheld, you may wish to discuss with a healthcare provider the options and the possible implications of your choices.

- **Include a copy of your advance care plan or advance directive in your Green Sleeve.**

YOUR ADVANCE CARE PLAN

These can be highly personal statements about what is important to you.

The messages might be very practical or they can be very philosophical.

They can serve as instructions, or even as legacy documents for your family about your life values and beliefs.

Everyone has a different story to tell and a different way to do it. A written statement will help guide your decision makers when the time comes to understand what decisions you would have made for yourself.

You can find links to examples of personal advance care plan documents on our webpage: www.coasthospice.com/acp

REPRESENTATION AGREEMENT: CLAUSE 7 INSTRUCTIONS OR WISHES

You can include instructions or wishes about your health care in your representation agreement. This would go in *Clause 7: Instructions and Wishes,* or could be noted on a separate page and attached to the form.

You can add specific directives, or you may just want to include a general statement about your wishes and beliefs around life, and death. You can also instruct your representatives and providers to refer to an advance directive.

ADVANCE DIRECTIVE

An advance directive is a legal document that records your wishes around accepting or refusing specific health care treatments. It must be signed by you and your signature must be witnessed.

If an advance directive isn't clear, specific, and relevant to the medical situation at hand, **it may be ineffective when needed most.** For this reason, advance directives are best used only when someone:

- Has a specific diagnosis with a predictable medical path
- Is nearing the end of life
- Is trying to get ahead of a condition they are genetically predisposed to
- Has a strong spiritual or personal belief that would prohibit certain treatments regardless of the circumstances
- Has no one who knows them well enough to make fully informed decisions on their behalf

- **If you have a specific illness, you know what decisions are coming, and you have strong values for or against specific treatments, you can create an advance directive.**
- **You can change or cancel an advance directive at any time.**

For more information on representation agreements or an advance directive, ***go to www.peopleslawschool.ca***

SUNSHINE COAST greensleeve ADVANCE CARE PLAN

A really important way to make sure your advance care plan is documented is to get your Green Sleeve package from Sunshine Coast Hospice or your healthcare provider.

Think of the Green Sleeve as your healthcare passport. It is a place to store your emergency medical information and advance care plan documents and to have them readily available in case of emergency or in anticipation of your declining health.

Make sure the location of your Green Sleeve is clearly marked or communicated in advance so that first responders and family members know where to find it.

You can take your Green Sleeve with you to medical appointments, treatments or hospital admissions.

YOUR GREEN SLEEVE SHOULD CONTAIN:

- ☐ Your emergency information form
- ☐ A list of all your medications
  You can get this from your doctor or your pharmacist
- ☐ Your MOST form or NO CPR form
  Your doctor will complete this form with you
- ☐ Your representation agreement or your temporary substitute decision makers list
- ☐ Your advance directive, (if you have one) or other personal wishes statement you want your family and/or decision makers to read

You can find fillable PDF forms for the emergency information form and the temporary substitute decision maker form on the Hospice website at www.coasthospice.com/acp

REVISIT AND REVIEW

Review your Green Sleeve periodically and whenever your health or personal situation changes to make sure your ACP documents are up-to-date, and communicate those changes to your loved ones and healthcare team.

RESOURCES

SUNSHINE COAST HOSPICE: Advance Care Planning resources
www.coasthospice.com/acp

BC MINISTRY OF HEALTH: Advance Care Planning
www.gov.bc.ca | MY VOICE: Expressing My Wishes for Future Health Care Treatment

FIRST NATIONS HEALTH AUTHORITY: Advance Care Planning
www.fnha.ca | YOUR CARE, YOUR CHOICES: Planning in Advance for Medical Care

PEOPLE'S LAW SCHOOL: Plan for your Future Care
www.peopleslawschool.ca | A very accessible resource for the legal problems of everyday life in BC

NIDUS PERSONAL PLANNING RESOURCE CENTRE
www.nidus.ca | A legal resource for information on Representation Agreements and other personal planning documents

THE CONVERSATION PROJECT --THIS LINK DON'T WORK
www.theconversationproject.org

BC CENTRE FOR PALLIATIVE CARE
www.bc-cpc.ca

SPEAKUP: CANADA'S NATIONAL ACP WEBSITE
www.advancecareplanning.ca

OTHER FINANCIAL AND LEGAL THINGS TO THINK ABOUT:

1. ORGAN DONATION

www.transplant.bc.ca

DID YOU KNOW?

- A single organ donor can save 8 lives, and their tissues and corneas can benefit 78 people.
- There is no age limit to becoming an organ donor. People in their 50s, 60s, 70s and beyond have been both organ donors and organ transplant recipients.

2. UTILITY AND SERVICE ACCOUNTS

Consider authorizing someone else in your household or family to be able to act on your behalf with utility companies, Canada Revenue Agency and other service providers. Arrange for direct deposits to, and pre-authorized payments from, your bank accounts.

3. PASSWORDS

Are there online accounts you want someone else to be able to access for you? Let them know where to find your passwords.

4. MEDICAL ASSISTANCE IN DYING (MAiD)

www.dyingwithdignity.ca

Medical assistance in dying is a legal right in Canada. Recent changes to the law (March 17, 2021) now allow MAiD for eligible persons who wish to pursue a medically assisted death, whether their natural death is reasonably foreseeable or not. Patients can speak to their doctor about what the criteria are and how to apply for the option to end their life with the assistance of a doctor or nurse practitioner.

5. POWER OF ATTORNEY

www.peopleslawschool.ca

A power of attorney is a legal document. With it, you can give someone you trust the power to look after your financial and legal affairs. This might include paying bills, depositing or withdrawing money from your bank account, investing your money, or selling your home.
There are different types of powers of attorney. It is important to talk to a lawyer to fully understand the best option for you.

6. WILLS AND ESTATES

www.peopleslawschool.ca

You don't have to prepare a will, but it's a very good idea to have one! If you don't have a will, BC law will determine how your estate is distributed, and that may not be what you would want. It also takes much longer, will cost more in fees to the estate, and will be much more stressful for the family. Preparing a will helps ensure fairness, accuracy, and peace of mind. It makes sure your wishes will be respected and your loved ones will be taken care of.

WITH GRATITUDE

TO OUR GREEN SLEEVE INITIATIVE COLLABORATORS:

Dr Carmen Goojha & Sunshine Coast Division of Family Practice

Community Paramedics, BC Emergency Health Services

The Health Care Team at shíshálh Nation

Our own Coast Hospice ACP volunteers

TO THE FOLLOWING PEOPLE AND ORGANIZATIONS FOR SHARING THEIR PASSION, EXPERTISE, RESOURCES AND GUIDANCE:

Patricia Byrne and the People's Law School

BC Centre for Palliative Care

Cari Hoffman and the ACP team at Fraser Health Authority

Barb Stack, Langley Division of Family Practice, and the Langley Medwatch Program

The staff and health care professionals at Vancouver Coastal Health and Sechelt Hospital

This booklet is not intended to provide legal or medical advice. It is merely for informational purposes.

A SPECIAL THANK YOU

To our Coast Hospice community donors and our 2022-23 funders

SUNSHINE COAST FOUNDATION

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