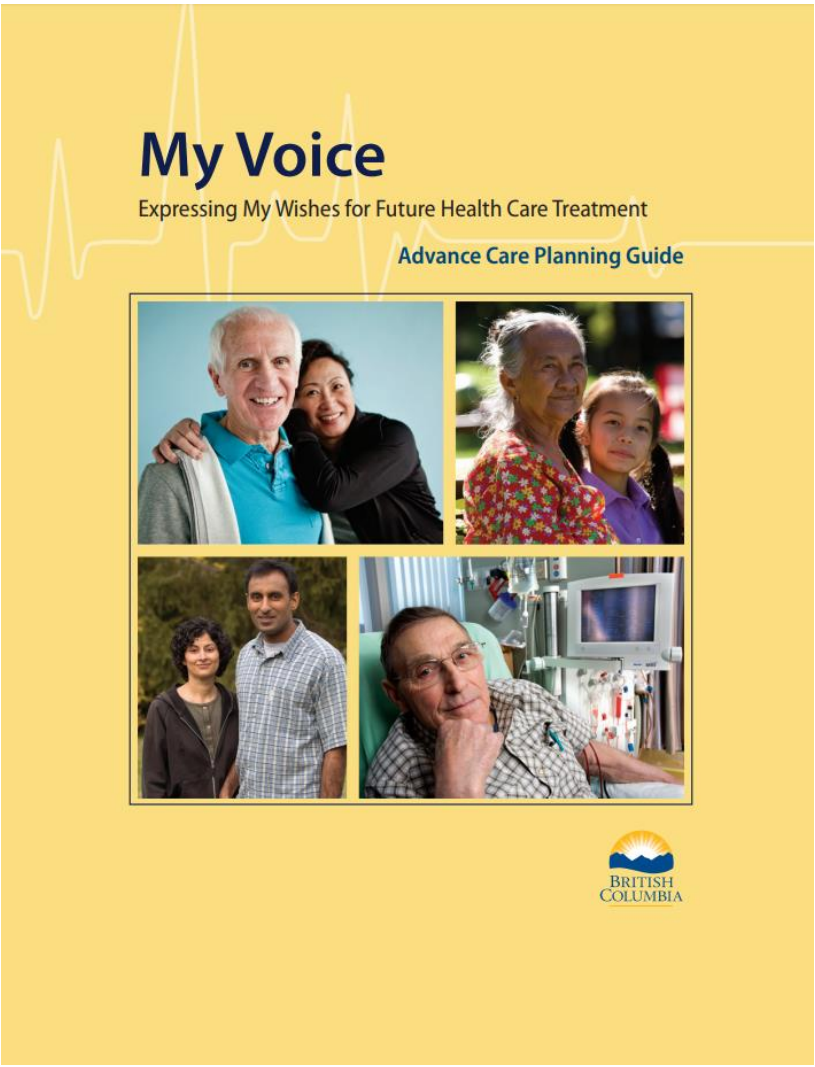
My Advance Care Plan

My Voice in Action: A Supportive Workbook to My Voice



This workbook belongs to: _____

Fraser Health Advance Care Planning
1-877-825-5034
advancecareplanning@fraserhealth.ca
www.fraserhealth.ca/acp

Contents

The orange boxes have important tips and information you should know about as you move through the workbook.

Introduction

This workbook can help you work through the steps of planning for your future health, known as Advance Care Planning or ACP.

It will help you start to make your own plan after you have learned about what advance care planning is. You can learn about Advance Care Planning by:

- Reading “My Voice: Expressing my Wishes for Future Health Care Treatment”.
- Talking with one of your health care providers
- Attending an Advance Care Planning workshop (see page 29)

The hope is this workbook will help you begin completing your own advance care plan.

How to use this workbook:
It is a good idea to read “My Voice” first before you begin.

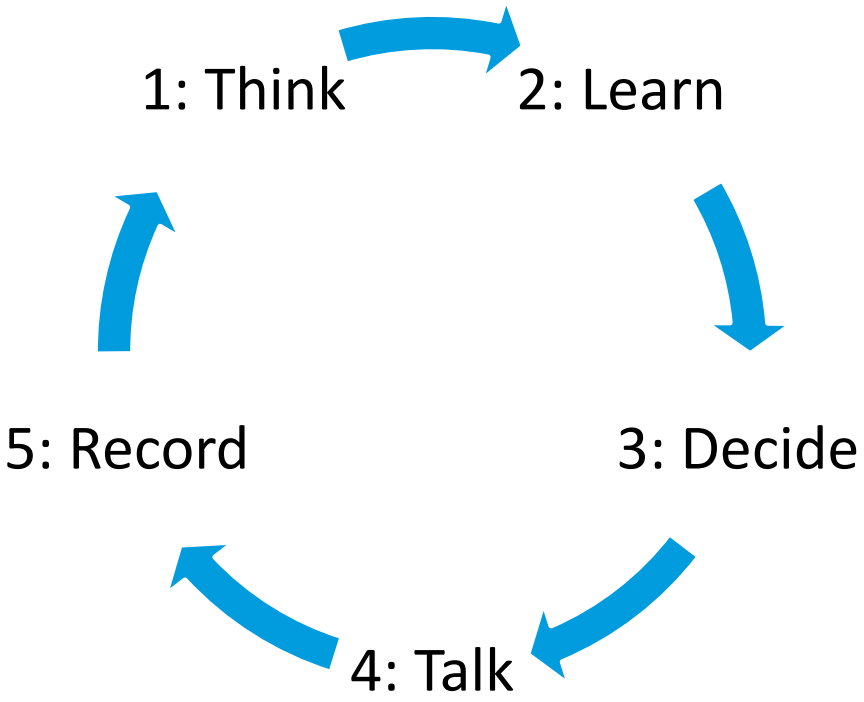
This workbook is for you to work through by yourself or with the people who matter to you. It might not answer every question, but it will help you get your thoughts together.

Writing your thoughts down does not replace talking to those close to you. Once your Advance Care Plan is put together, share it with the people who matter to you, as well as with your doctor, nurse, social worker or other health care providers who help you.

Take your time. Your Advance Care Plan does not have to be filled out all at one time. You might start, and then realize you need to talk to your doctor or friend more. It is meant to be done as you need it, and will likely change over time. You can always change your mind as things in your life change.

Think, Learn, Decide, Talk, and Record

The Five Steps of Advance Care Planning



Advance care planning means thinking about what matters to you, what a good day looks like, your values and wishes for future health and personal care, then sharing your wishes with others. It also means deciding who will speak for you if you cannot speak for yourself. It is a way to give those who matter to you the confidence to make decisions on your behalf when you are not able to.

For more about Canada's National Advance Care Planning five step process:
www.advancecareplanning.ca

Speak Up

My Advance Care Plan

STEP 1: Think

Beliefs, Values, and Wishes

What matters most to me? What or who influences my life?

Thinking about your beliefs, values, and wishes may seem hard to do at first. However, as you work through the questions below, you will see that we are asking you to think about your personal values. We all live our lives within unique values, whether we know it or not. We show our values through our daily actions. Our daily actions are how we express what is important in our lives. Reflecting on your personal values, and their importance, helps you to make decisions related to your health care.

What makes my life meaningful?

Think about… what is a good day? What do you do for fun? How do you like to spend your time?

Examples could include:

- Spending time with those who matter to me or being alone
- Practicing my spirituality
- Being active or being outdoors

What do I value most about my mental and physical health?

Examples could include:

- Living my life with some help or without help
- Having my privacy or being around people
- Having those who matter to me nearby

I would find the following situations or conditions difficult:

Examples could include:

- Staying in bed and needing help with getting around
- Not being able to talk with others
- Being in pain
- Leaving things undone that I haven’t had a chance to do
- Coping with my emotions and those of my family/friends

STEP 2: Learn

My Health

What do I need to know about my health?

How much do I like to know about my health?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I do not like to know anything		**I like to know a little at a time**		**I like to know everything**

How do I like to make health care decisions?

Check:

- ☐ By myself
- ☐ Shared, by involving those who matter
- ☐ Others decide for me
- ☐ Other:_____

What is going on with my health?

My Health Conditions (issues, problems, etc.):

How much do I know about my health conditions?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I do not need more information		**I need a little more information**		**I need a lot more information**

How much do I know about what is likely ahead with my health conditions?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I do not need more information		**I need a little more information**		**I need a lot more information**

I have thought about medical treatments I might want or not want. I have thought about:

It is important to talk this over with your doctor, nurse, or other health care providers.

You may still need more information.

Some questions I have about my health condition or different treatments include:

Other examples of questions you may want to ask your care provider:

- What health conditions do I have?
- What does my health condition mean for me?
- What will my health condition look like in the future?
- What are possible treatments?
- What possible problems might I face down the road?
- What do you think may lead to the end of my life?

Thinking ahead about treatments is important but there may come a time when the care you want is not right for you. Some wishes may not be possible to follow. Some values may need to be traded off to meet the demands of your situation. For example, changes in your health may mean a treatment you wanted before may no longer help you, or may harm you. Talk to your health care providers and find out what would be of benefit for you.

Health Care Decision Tool: B.R.A.I.N.

If you are currently facing a health care decision:

Here is a tool to help when you need to make health care choices.

First, find out what treatment is being suggested from your health care team then ask yourself…

B	**Benefits**	What are the benefits of this procedure/treatment?
R	**Risks**	What are the risks of this procedure? How might this negatively affect me and/or those who matter to me?
A	**Alternatives**	Are there alternatives to this procedure or treatment? Are there other options?
I	**Intuition**	What is my gut feeling about this?
N	**Need Time** or **Nothing**	Can I delay this procedure or treatment and take some time to think about it? Can I discuss it with the people who matter to me? What will happen if I choose to do nothing for now?

Regardless of the medical treatments that you get or do not get, your health care team will always provide medicine and treatments to help make you feel better.

For example, when you are in pain or feeling dizzy or sick, health care providers will always offer you:

- Pills for infection (antibiotics) or to reduce pain
- Medicines or treatments to help with breathing
- Surgery to control pain or other issues

STEP 3: Decide

Substitute Decision Makers (SDMs)

Who would speak for me if I couldn't speak for myself?

If you cannot make your own health care decisions (not capable) and a medical treatment is offered, someone will be needed to speak on your behalf. The order of the people who qualify is set out by BC Law.

If you were unable to speak for yourself and someone was going to make medical decisions on your behalf…

What kind of person would I want them to be?

Examples could include:

- Good at talking with doctors, nurses, health care providers, and my friends/family/those who matter to me
- Know about my current health issues
- Calm in a crisis and when there is conflict

Who do I talk with about important things?

Who knows me the best?

Could this person honour my wishes?

Yes or No? Why not?

Substitute Decision Makers

The people who make health care decisions on behalf of others are set out in BC Law. You can legally choose someone through a Representation Agreement (My Voice, pg. 16).

Otherwise, health care providers will follow a legal list set out by the law called the Temporary Substitute Decision Maker (TSDM) list. To qualify as a TSDM, the person must be 19 years old, willing, capable, have no dispute with you, and have been in contact with you in the year before you needed health care. If a TSDM is necessary, your health care provider will follow the law and contact the first person on the list who is qualified and available.

Sometimes the set legal TSDMs are not the best decision makers for us, and that is okay. Remember, this is not a competition. This is not about choosing who you love the most. Even if you decide to legally choose someone (make a Representation Agreement), your TSDM list is still needed.

All decision makers must honour and respect your values, beliefs, wishes, and instructions.
If you don't tell them, they won't know.

My Temporary Substitute Decisions Maker (TSDM) List:

Spouse

(includes married, common-law, same sex. Length of time living together does not matter)

Name	Phone

Adult Children (birth order does not matter)

Name	Phone	Name	Phone

Parents (may include adoptive)

Name	Phone	Name	Phone

Brothers or Sisters (birth order does not matter)

Name	Phone	Name	Phone

Grandparents

Name	Phone	Name	Phone

Grandchildren

Name	Phone	Name	Phone

Anyone else related to me by birth or adoption

Name	Phone	Name	Phone

Close Friends

Name	Phone	Name	Phone

A person immediately related by marriage (equally ranked)

Name	Phone	Name	Phone

How do I feel about my list?

☐ I am okay with my list

☐ I am **not** okay with my list

If the order of the Temporary Substitute Decision Maker list does not work for you and you would rather, for example, have your friend and not your brother be asked to make health care decisions for you. Then you may wish to complete a **Representation Agreement**.

In this situation, you may ask for your brother to be included in discussions but feel your friend copes better under stress. It is suggested you talk with your brother about your wishes and ask that he support your friend in their role.

STEP 4: Talk

Start the conversations

One conversation can make all the difference. Imagine the difference 10 conversations could make…

Now that I've started to think about this, who do I want to talk to?

Who else?

When is a good time to talk to them?

Think about when you might approach those who matter to you – for example, at a social gathering, before your next big trip etc.

Where is a good place to talk?

Think about where you might have the conversations – for example, at the kitchen table, at a restaurant, during a walk etc.

What do I want to be sure to say?

List the most important things you want to say during your conversations.

Conversation Starters

Be Straight Forward:

“I want to talk with you about what is important to me.”

“I want you to be prepared if you had to make decisions on my behalf.”

Find an Example From Your Family or Friends:

“Do you remember my friend Frank who was in a coma for a while? I wonder if there were any fights in the family about keeping him on that breathing machine.”

Blame Someone Else:

"Pastor Jones was talking about our choices for health care if something happened, and I realized that I haven’t told you about my wishes – we should talk about that."

Find an Example From the News:

"That story about the family fighting about their mom’s care made me realize that we should talk about these things so the same thing doesn’t happen to our family."

STEP 5: Record

Write down your plan

… or make a video, or an audio recording.

Take this workbook, "My Advance Care Plan" and put it in your Greensleeve on your fridge.
This is where first responders (ambulance, fire) will look for it in an emergency.

Take your Greensleeve to all medical appointments and hospital admissions.

Other planning papers that I keep in my Greensleeve are:

- ☐ In Case of Emergency (this workbook, page 18)
- ☐ Medical Order for Scope of Treatment (MOST)
- ☐ Provincial No Cardio Pulmonary Resuscitation (No CPR)
- ☐ Representation Agreement (My Voice, pg. 32- 49)
- ☐ Advance Directive (My Voice, pg. 50, 51)
- ☐ Previous Advance Care Plans

Other planning papers that I might keep:

- ☐ Enduring Power of Attorney (financial and legal matters)

  _____

- ☐ Will (estate after death)

  _____

- ☐ Life insurance policy

  _____

- ☐ Funeral arrangements

  _____

Are you an organ donor registered with BC Transplant?

☐ Yes ☐ No

Other important papers can be found here:

Information a health care provider might ask you in an emergency

If you experience a health emergency and call 9-1-1, you or the people you are with will be asked to provide medical information.

It is recommended that you complete the following page and keep it in your Greensleeve.

In Case of Emergency Form

If you ever experience a medical emergency, call **9-1-1**

Personal Information

Name:	
Birthdate:	
Personal Health Number:	
Address:	
Phone Number:	
Languages spoken:	
Date completed:	
Date last reviewed:	
Important things to know about me:	

Examples of important things to know about you:
I wear a hearing aid, my spouse has memory problems, I have 2 dogs that live with me, my child has a disability – call my sister.

Emergency Contacts

The person(s) I want you to contact for more information is:
The people who make my health care decisions if I am not able to: Please see my representation agreement or my Temporary Substitute Decisions Maker list. It is in my Greensleeve.

Health Care Providers

Family Doctor/ Nurse Practitioner	Name:
	Phone number:
Specialist Doctor	Name:
	Phone number:
Specialist Doctor	Name:
	Phone number:

Allergies

I am allergic to:	
Kind of reaction:	
What to do:	
I am allergic to:	
Kind of reaction:	
What to do:	
I am allergic to:	
Kind of reaction:	
What to do:	

Health Conditions and any Surgeries

Medications (including non-prescription)

Where they are kept: _____

Drug:	Dosage:
Taken for:	

Drug:	Dosage:
Taken for:	

Drug:	Dosage:
Taken for:	

Drug:	Dosage:
Taken for:	

Drug:	Dosage:
Taken for:	

Drug:	Dosage:
Taken for:	

Drug:	Dosage:
Taken for:	

Future Action Plans

What actions will you take, now that you have learned about Advance Care Planning? Consider what you will do, who you will do it with, and what you may need to move forward.

What will you do, or do differently?

Examples could include:

- I will speak up more about my wishes and preferences
- I will complete a Representation Agreement

Who will you include in these actions?

Examples could include:

- I will organize a time to speak with my children
- I will ask my sister to go with me to my next doctor's appointment

What further information do I need??
Examples could include:

- I will make an appointment with my doctor or nurse practitioner to talk about my health
- I will review the papers that are in or go into my Greensleeve
- I will read about my health condition on the HealthLink BC site
- For further questions,
  I will contact the Fraser Health Advance Care Planning Team
  1-877-825-5034 or advancecareplanning@fraserhealth.ca

Don't forget to…

- Read "My Voice" for more information
- Share this plan with the people who are important to you and your health care providers.
- Record and update your plan regularly.
- Consider any legal documents that may be relevant to you.

"People have priorities besides just surviving no matter what. You have reasons you want to be alive. What are those reasons?"
- Atul Gawande

Definitions

Advance care planning record is a Fraser Health communication tool for health care providers to document advance care planning conversations they have with patients/client's and the people important to them.

Advance Directive is a capable adult's written instructions that speak directly to their health care provider about the health care treatment the adult consents to or refuses. It is effective when the capable adult becomes incapable and only applies to the health care conditions and treatments noted in the Advance Directive.

Cardiopulmonary resuscitation (CPR) is an emergency procedure used to attempt to revive someone when their heart and/or lungs stop working unexpectedly. CPR can include repeated compressions to the person's chest and rescue breathing to inflate the person's lungs and give oxygen.

Incapable (incapability) is determined by a health care provider who must base their decision on whether or not the adult demonstrates that they understand:

1. The information given about their health condition;
2. The nature of the proposed health care including risks, benefits and alternatives; and
3. That the information applies to their situation.

Life support and life-prolonging medical interventions are health care treatments like tube feedings, ventilators (breathing machines), kidney dialysis, medications, and cardiopulmonary resuscitation. They are considered medically appropriate care when the goal of care is to continue or prolong life.

Medical orders for scope of treatment (MOST) is a doctor/nurse practitioner's order for cardiopulmonary resuscitation (CPR) and a range of medical treatments. These offers for treatment are based on Advance Care Planning conversations which explore values and goals. Conversations occur between the health care provider and patient/client.

Power of attorney (POA) is a legal document that appoints a person (called an attorney) who is authorized by a capable adult to make financial, business and/or property decisions on their behalf. Attorneys may not make health care treatment decisions.

Representative is a person 19 years or older who is named by a capable adult, in a Representation Agreement, to make health care treatment decisions on their behalf when they are incapable of deciding.

Representation agreement (RA) is the document in which a capable adult names their representative to make health care and other decisions on his/her behalf when incapable. There are 2 types:

1. Section 7 RA: Adult may authorize a representative to make decisions about the routine management of financial affairs, personal care and some health care decisions on behalf of the adult, excluding decisions about the refusal of life support and/or life-prolonging medical interventions.
2. Section 9 RA: Adult may authorize a representative to make personal care and health care decisions on behalf of the adult, including decisions about the acceptance or refusal of life support and life-prolonging medical interventions.

Substitute decision maker is a capable person with the authority to make health care treatment decisions on behalf of an incapable adult, and includes a personal guardian (committee of the person), representative, and/or temporary substitute decision maker.

Temporary substitute decision maker (TSDM) is a capable adult chosen by a health care provider to make health care treatment decisions on behalf of an incapable adult when care is needed. A TSDM is not chosen if the adult has an advance directive that addresses the care needed at the time, or if the adult has an available personal guardian or representative.

Additional definitions can be found on page 22 of ‘My Voice’.

Where to find…

QR Code

Consent to organ donation
transplant.bc.ca

Online copy of My Voice
healthlinkbc.ca/health-feature/advance-care-planning

British Columbia Provincial No CPR form
healthlinkbc.ca/health-feature/no-cpr-form

Fraser Health Advance Care Planning
general information and workshops/presentations
www.fraserhealth.ca/acp

A QR code (short for 'quick response' code) is a type of barcode that you scan with your smart device's camera. Once scanned, it takes you to that web page.

References

Canadian Hospice Palliative Care Association. (2015). *Speak Up British Columbia Work Book.* Retrieved from www.speak-upinbc.ca

Institute for Health Care Improvement. (2017). *Your Conversation Starter Kit* [PDF file]. Retrieved from theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf

Massachusetts Coalition for Serious Illness Care. (2019). *Good Talk Toolkit.* Retrieved from maseriouscare.org/toolkit

The Regents of the University of California. (2012). *Prepare for your Care, Question Guide* [PDF file]. Retrieved from prepareforyourcare.org/content/default/common/documents/PREPARE-Questions-English.pdf

My Notes:

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Advance Care Planning

FRASER HEALTH

For more information contact or visit:

1-877-825-5034

advancecareplanning@fraserhealth.ca

www.fraserhealth.ca/acp

www.fraserhealth.ca

This information does not replace the advice given to you by your healthcare provider.

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