



My Voice In Action:

A Workbook for Advance Care Planning

Easy Read Version.

This A	dvance (Care Plan	belongs to:	

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Caregivers and Support People

The blue boxes have important messages for caregivers and support people. Caregivers need guidance too so they can support others in this process.

Two tips to get started:

- Start this process as soon as possible
- Self care is important. If you are a caregiver, remember to take care of yourself too.

Note: If you're using the digital version of this booklet, be sure to save it to your computer before typing in your answers. Otherwise, what you type will not be saved.

Fraser Health Advance Care Planning 1-877-825-5034 advancecareplanning@fraserhealth.ca fraserhealth.ca/acp This workbook can help you, and the people who matter to you, work through the steps of planning for your future health.



This is known as Advance Care Planning or ACP.

This easy-read version is simplified to help anyone who may process information differently:

- People living with brain conditions such as Dementia,
 Huntington's disease, ALS, Parkinson's disease, or tumors.
- People living with impairments from health events such as aphasia from Stroke or other limitations from Brain Injury.
- People living with disabilities.
- People with limited English literacy (when translation is not available).

How to use this workbook:

Start by yourself or with someone else.



Talk about your plan.



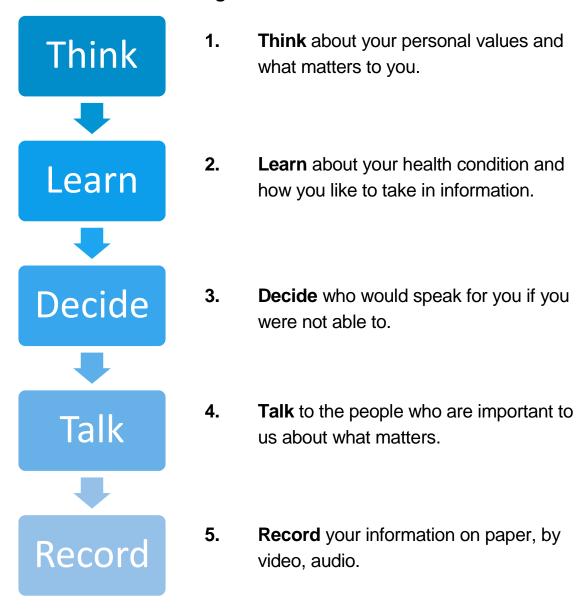
Take your time.



Review and add to it as you need.



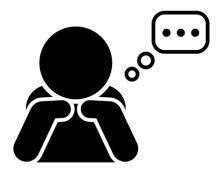
Advance Care Planning means:



Advance care planning is not a single event. It is a process; a lifelong process for everyone.

Planning is a way to give those who matter to you the confidence to make decisions on your behalf when you are unable to.

Step 1: Think



Beliefs, Values, and Wishes. What matters most to me?

Thinking about your values may be hard to do at first. You show your values through your daily actions.

Actions are how you show what is important to you. Reflecting on your values, and their importance, helps you to make decisions related to your health.

Caregivers and Support People

Step 1: Think

Identifying values can be challenging for everyone.

Helping someone else with this process can be even more difficult. So, asking the right questions or providing prompts can be especially helpful.

Examples of questions or prompts:

- What makes you happy?
- What do you do for fun?
- What are your favourite foods, movies, activities, or places?

Think about and share what things you have observed them do that brought them joy or meaning.

Try not to speak for the other person – remember that our values are unique and individual so there is no need to judge or question what is important to them.

Values and beliefs are neither right nor wrong.

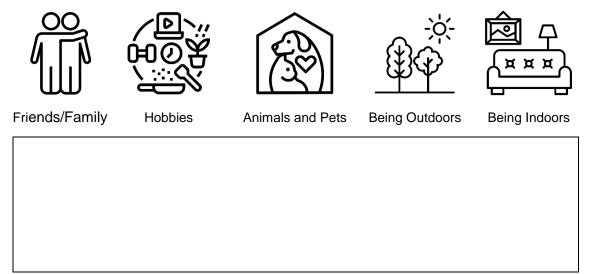
Worksheet- Step 1, Think



What makes my life meaningful?

What does a good day look like?

Examples of what might make my life meaningful:





What is most important about my mental and physical health?

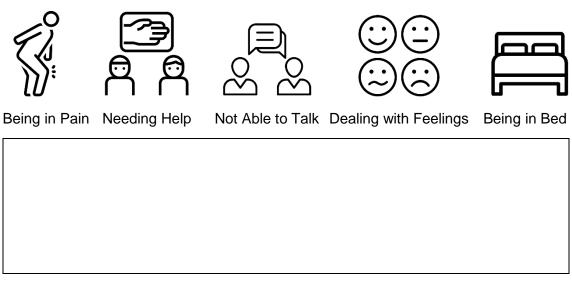
Examples of what might be most important:





I would find the following health situations difficult:

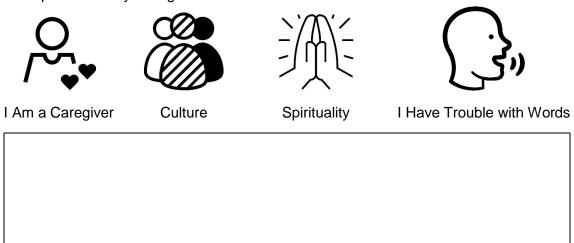
Examples of situations:





Something I want my Health Care Provider to know about me:

Examples of what you might want them to know:



Step 2: Learn



What do I need to know about my health?

Knowing how you like to take in information is important for clear communication.

Learning about your health and about the law helps you be ready for making health care decisions. You might make different decisions if you know more.

Caregivers and Support People

Step 2: Learn

People with early stage disease or mild symptoms after a health issue often experience anxiety about their diagnosis and the limitations it has caused. It's important not to dismiss these feelings – instead use it as an opportunity to establish yourself as someone they can really talk to: "Tell me more..."

Thinking ahead about treatments is important but there may come a time when the care they want is not right for them.

For example, changes in their health may mean a treatment they wanted before may no longer help them, or may harm them.

Talk to your health care provider and find out what would be of benefit.

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

Worksheet – Step 2, Learn

How much do I like to know about my health?						
	1	2	<u></u> 3	<u> </u>	<u> </u>	
		l like to know		l like to know		
Kne	ow anything		little at a time		everything	
	What is g	joing on with	my health?			
		n Conditions (i		ems):		
		`		<u>, </u>		
	How do I	like to make	health care d	ecisions?	•	
	Most of th	ne time:				
1			LO-	٦	0	
	\mathcal{L}	<u>ح</u> م	\ ↑ 🞞	┽	$\overline{(2)}$	
		<u>~</u>		<u>ر</u>		
Bv	Myself	With Others	Others Decide	For Me	Other	
,						

How much do I know about what is likely ahead with my health conditions?						
	1	_ 2	<u> </u>	<u> </u>	<u> </u>	
	lo not need e information	l need a l	ittle more inforr	mation	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 conditions or different treatments are:						
Exam •	•	alth conditions i	to ask your healt mean for me and be ahead for me	l my life?	r:	

Step 3: Decide



Substitute Decision Makers (SDMs).

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

Struggling to make your own decisions or to communicate with others can happen slowly, or it can happen overnight.

If you are not able to talk, someone will need to make medical decisions for you.

Caregivers and Support People

Step 3: Decide

If an adult is not able to make their own health care decisions, someone will need to decide for them.

The people who make health care decisions on behalf of others are called substitute decision makers (SDMs). This is already set out in a specific order by British Columbia laws (see My Temporary Substitute Decision Maker List, page 10).

Health care providers will contact the first person on the list who is available, qualified, and able to carry out the responsibilities according to the law.

Worksheet - Step 3, Decide



Who do I talk with about important things?

Who knows me the best?

Examples of pe	eopie wno mignt kno	w you best:				
Family	Friends	Caregiver/Support F	People Other			
Moul	d this ways are a	r no onlo follow m	v wishes 2			
would	a this person o	r people follow m	y wisnes?			
Yes o	r No? If no, why	not?				
My Ta	omnorary Subs	tituto Docisions M	Jakor (TSDM) List:			
IVI Y I C		litute Decisions iv	laker (TSDM) List:			
Spouse						
•	ed, common-law, sam	e sex. Length of time livi	ng 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 Sis	ters (birth order do	es not matter)					
Name	Phone	Name	Phone				
Grandparents	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 you do not like your list, ask your caregiver or support person to help you learn how to choose the person you want.

Caregivers and Support People

Step 3: Decide

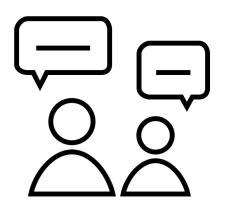
Sometimes the set legal SDMs are not the best decision makers for us, and that is okay. If they do not like the order of their list, remind them that they may legally choose someone they want through completing a Representation Agreement.

Even if they decide to legally choose someone by making a Representation Agreement, a TSDM list is still needed in case we can't reach their representative.

All decision makers must legally honour and respect the person's values, beliefs, wishes, and instructions.

For some adults, they might not have any close friends or family in their lives. Or sometimes the people involved are not able to fulfill their roles to make substitute health care consent decisions. If this is the case, a health care provider will ask the Public Guardian and Trustee to give consent on behalf of that adult when a health care decision is to be made. The Public Guardian and Trustee's duty is to help protect the adult.

Step 4: Talk



Start talking

You might think that those close to you will know what matters most to you, but if you don't tell them, they won't know.

Sharing this information ahead of time helps the people who matter to you make the right health care decisions in the moment they are needed.

These conversations also help you feel less anxious and more in control of your health. Talking while you are doing okay is the best time. Keep talking, what's important to you may change over time.

Caregivers and Support People

Step 4: Talk

Some people will experience steady decline of their disease but symptoms are not always the same all the time. Use those good days or moments of clarity to have conversations.

Conversations should be short and simple, but also frequent.

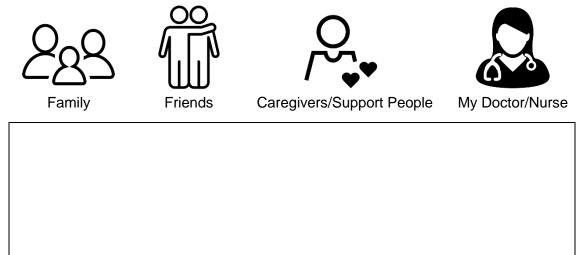
Having this conversation and doing your own advance care planning is important for you too.

Worksheet - Step 4, Talk



Who do I want to talk to about my plan?

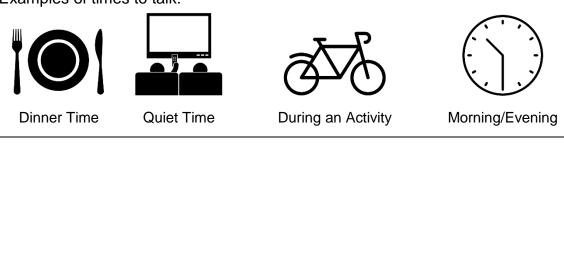
Examples of you might want to talk to:





When is a good time to talk to them?

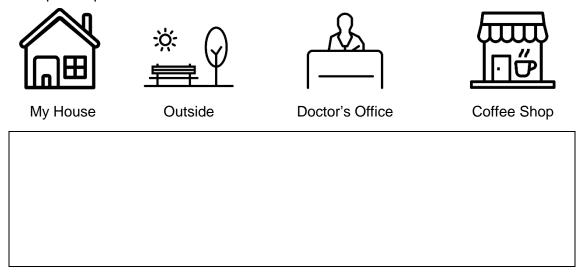
Examples of times to talk:



>

Where is a good place to talk?

Examples of places to talk:



Share everything you've recorded or thought about so far.

Step 5: Record



Write down your plan.

Or make a video or audio recording.

Record your thoughts and feelings as a helpful reminder to the people who are important to you.

These notes, videos, or audio recordings can be helpful in case someone needs to make a health care decision for you.

Caregivers and Support People

Step 5: Record

In Fraser Health, we ask that people to keep important pieces of information in the Greensleeve. This green folder should go with the person you are caring for to medical appointments or the hospital.

Other planning papers to keep in the Greensleeve are:

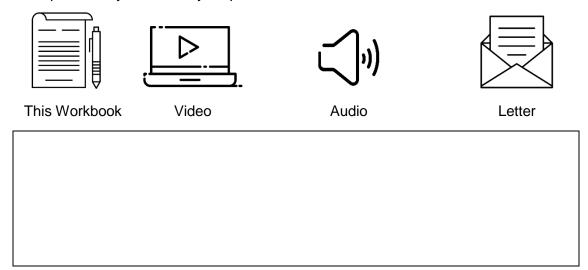
- In Case of Emergency form
- Medical Order for Scope of Treatment (MOST)
- Provincial No Cardio Pulmonary Resuscitation (No CPR)
- Representation Agreement
- Advance Directive

Worksheet - Step 5, Record



How do I want to record my plan?

Examples of ways to record your plan:





Take your advance care plan and put it in your Greensleeve. Then place it on your fridge.

This is where ambulance and fire people will look for it in an emergency at your home.

Bring your Greensleeve to all medical appointments and hospital visits.

Go to page 18 for more information on how to get a Greensleeve.

For More Information

Where can I get more information about Advance Care Planning? How do I get a Greensleeve?

Visit: fraserhealth.ca/acp

Call or email Fraser Health at: 1-877-825-5034

advancecareplanning@fraserhealth.ca

Where can I get more information about legal documents such as Representation Agreements and Advance Directives?

Visit: peopleslawschool.ca



fraser**health**

Where can I learn more about Dementia and/or Alzheimer's?

Visit: alzheimer.ca/bc/en

Alzheimer *Society*

Where can I learn more about Stroke?

Visit: heartandstroke.ca



How I can I communicate better with someone who is experiencing aphasia?

Supported Conversation for Adults with Aphasia (SCA[™]) developed by the Aphasia Institute is a recommended tool.

Visit: aphasia.ca



I am an adult with a developmental disability. Who can help me with this?

Visit: communitylivingbc.ca



Contact Us

For more information, contact or visit:

1-877-825-5034

advancecareplanning@fraserhealth.ca <u>fraserhealth.ca/acp</u>



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

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- 11. Outdoors by Made x Made
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- 17. Eating by Kiew Thi Kim Guong
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- 31. About us by Ben Peetermans
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- 34. Talk by Mundo
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- 40. House by DinosoftLab
- 41. Park by Yeoul Kwon
- 42. Doctors Office by Wojciech Zasina
- 43. Coffee Shop by Komkrit Noenpoempisut
- 44. Multimedia by Evon
- 45. Workbook by Iconika
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