

Information Booklet for Advance Care Planning



Planning for Future Healthcare Choices

Life choices

Imagine... Without warning, you have developed a life-threatening illness and are in an intensive care unit of a hospital. You can no longer recognize people or communicate with anyone. Despite the best medical treatment, your doctors believe you probably will not leave the hospital alive. However, artificial life support can keep your heart beating and your lungs breathing almost indefinitely.

What would be *your* goals for medical treatment in this situation?

You make choices on a daily basis – choices about where you want to live and who you pick as your life partner; choices about which career to follow, what type of home you want to live in, and your ideal life-style.

One of the most important choices facing you is your choice for future medical care.

Who decides when enough is enough?

You do...or at least you should.

You should decide about the kind of medical care you want while you are capable of making your own decisions.

Technology today has advanced to a point where patients with little or no hope of recovery can be kept alive indefinitely. This fact has made it more important than ever for people to express how they feel about prolonging life and decide what kind of care they would want if they became unable to make their own decisions.

Think about the kind of treatments you would want, and not want, if you became too sick or injured to tell hospital staff your wishes. If you need to, find out more about the available medical choices from your doctor or other sources of health information.

Talk about the kind of care you want and don't want with the people closest to you, as well as your doctor. Talking about these issues may not be easy; you may face resistance, even denial, from those closest to you because they may be uncomfortable talking about living at the end of life. Asking those close to you to make decisions on your behalf can be difficult too, but discussing your choices with them will reassure them.

Encourage those closest to you to find out about new medical treatments if you fall seriously ill or are injured. New procedures and drugs may have become available since you discussed your wishes with them. These new treatments could be suitable for you if they also honour the values and goals you expressed earlier. The decision-maker you choose should be willing to gather new information on your behalf as it will be helpful in selecting suitable medical care for you, if you cannot.

Then write your wishes down. Fraser Health has a workbook called *My Voice* that can help you.

Gifts we can give our children

My mother gave me a very loving and insightful gift – namely, careful direction about what to do if she became irreversibly ill and unable to make her own decisions. Within a few years, she was the victim of Alzheimer's disease. My mother was unable to understand her health care or make any decisions because of the impairment in her judgment and the complexity of her situation. I became her advocate and relied on the direction she had given me earlier.

My first experience in decision-making occurred when the doctor discussed the resuscitation issue with me. He asked, "We need to know what your mother's choice would be if her heart should stop." Mom had prepared me for this – the answer was not to initiate resuscitation. Few illnesses along the way required much decision-making, which was fortunate for us. But I do think I would have known what she wanted and acted accordingly.

When my mother died, amidst the sadness, there was peace. Peace in knowing that she had said many times to me, "No medical intervention when there's nothing that can be done for me." I am grateful that I didn't have to struggle with decisions during that time.

Imagine... You are living in a nursing home because your ability to make your own decisions has gone. You can feed yourself and connect a little with people, but it is not a meaningful connection. You no longer know who you are or what happens from one moment to the next; you cannot recognize your family or friends. (A disease like Alzheimer's can cause this to happen.) You will not improve and will likely get worse over time.

What would be *your* goals for medical treatment in this situation?



Understanding Advance Care Planning

Advance Care Planning is a process of personal reflection and then action. Here's what it looks like:

1. You consider what makes life meaningful to you and what circumstances might make life pointless for you. This reflection helps you identify your values and beliefs around end-of-life issues.
2. You learn about current medical treatments for the very ill or injured and their implications.
3. You choose what medical care you want, and don't want, that honours your values and beliefs.
4. You discuss your choices and wishes with those closest to you so they know what you would want in a variety of situations. You also choose an individual to speak for you if the time comes when you cannot make your own medical decisions.
5. Lastly, if you wish, you put your Advance Care Plan in writing.

Effective planning is the best way to make sure those closest to you and your healthcare providers respect your wishes. Completing this process will provide great comfort to you and strength to those who may have to make important medical and end-of-life decisions for you.

More about Advance Care Plans

You may know Advance Care Plans by a different name. You may have heard them referred to as living wills or advance directives. In Fraser Health, we use the name Advance Care Plan.

Advance Care Plans are made by you, for you. You must be over 19 years old to make a plan and you cannot make an Advance Care Plan for someone else.

You can make your Advance Care Plan verbally or in writing; however, Fraser Health advises putting your plan in writing. A written plan helps people accurately remember what you want and makes it easier for them to communicate your wishes to healthcare providers who do not know you.

An example of the thinking that you need to do:

If you were in one of the imaginary situations on the previous pages, what would you like to happen? What would be *your* goals for treatment?

- To prolong your life with medical treatments? (These can include medications, life support measures, surgery, and/or feeding tubes.)
- To keep you comfortable and maintained at the highest level of function possible? (Usually medications can control pain and other unpleasant symptoms while allowing a natural death to occur.)

A doctor's story



I had a patient with a serious lung disease that made him very short of breath and immobile. We talked about what he would want us to do if his lungs failed. He decided against using a breathing machine (ventilator) in this situation. His wife supported his choice and my patient stated his wishes in a written Advance Care Plan, which he knew would relieve his wife of trying to guess what he would want in an inevitable medical crisis.

Six months later, he came to the hospital hardly able to breathe. Without a ventilator, he would die. The doctor on

duty, who did not know him, asked him what he wanted them to do. He repeated he only wanted to be kept comfortable and didn't want assistance from a breathing machine. The doctor was uncertain if his lack of oxygen was affecting his judgment. Then my patient's wife showed the hospital staff her husband's carefully considered, written Advance Care Plan. Even though he was still able to speak for himself, the plans he had made ahead of time supported the decisions he made when he was very ill.

The medical staff respected his choices and he died comfortably without the use of a machine. Discussing his medical care in advance, with both his family and doctor, made his final hours less traumatic.

Your doctor needs to know about your concerns, your fears, and your decisions.

Answers to commonly asked questions

How can I talk about end of life issues with my family?



Just because you have a close relationship with a relative or friend does not necessarily mean you know what choices they might make for your future medical care in a crisis. Plan for yourself first and then let your family or friend know what you want. Explain to them that you don't want them feeling anxious about making decisions for you. Then ask them to tell you what they think about your choices.

Who do I talk to?

Talk to those who are close to you and most likely to be involved in decision-making if you are very ill.

What would I talk about?

1) You should discuss who would make these medical decisions for you and how they would do it. Make sure the person you choose to represent you not only knows what you want, but is able to make complex decisions in difficult situations. Allow them to say no if they feel the situation may become too hard for them, and choose another spokesperson.

2) Talk about your goals for medical treatment if you had a serious, advanced medical illness or injury that interfered with your ability to communicate. For example, how bad would such an injury be for you to say, "Don't use medical treatments to keep me alive in that state!" Many simply say, "Don't keep me alive if I am a vegetable!" If you feel that way, describe what it would mean to you to "be a vegetable."

Do I need to talk with my doctor?

Where possible, you should talk with your doctor to make sure your planning is clear and complete. Your doctor can also help you in making your plan one that health care providers can respect and follow.

More About Advance Care Plans:

*"I had a brain injury thirteen years ago...and I would like to learn more about end-of-life preparations."
Resident in the Fraser Health area, February 2006*

When is an Advance Care Plan used?

As long as you are capable of making your own decisions, you remain in control of your own medical care. If you're unable to make your health care decisions, your wishes in the Advance Care Plan would guide decision-making.

Can my Advance Care Plan be changed?

Yes. You can change your Advance Care Plan at any time, as long as you are capable of making decisions. If you fill one out, you can have a copy put in your medical file.

What if I am injured or become ill when I am away from home?

The best way to ensure that you receive the type of care you want, if you cannot speak for yourself, is to discuss your wishes with your chosen decision-maker. Make sure that this individual has a copy of your Advance Care Plan. Also, take a copy of your plan with you when you go away – the chances are good that health care providers will respect your Advance Care Plan.

What happens in an emergency?

In the event of an emergency, life-sustaining measures may be started, possibly before your medical record is available. Treatment can be stopped if it is discovered that it's not what you would have wanted.

How do I get started on my Advance Care Plan?

For more information about Advance Care Planning in Fraser Health and a helpful form for your use, please call:
1-877-TALK-034 (1-877-825-5034)
or visit:
www.fraserhealth.ca





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