



ePAC
EQUITY IN PALLIATIVE APPROACHES TO CARE

My Advance Care Plan User Guide



vancouver
foundation



CIHR IRSC
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For more information and to access the ePAC Advance Care Plan visit www.equityinpalliativecare.com

INTRODUCTION

Advance care planning is thinking, talking, and writing about what's most important to us. If we get really sick or are in an accident and can't speak for ourselves, our friends and family can look to our Advance Care Plan (ACP) to help them make decisions about our care. While it can be hard to think about the future, having these conversations can help us prepare and ensure that what is important to us is respected.

Advance care planning is not about giving over our power to make decisions. It's about saying how we want and deserve to be treated. It's about naming the people who know us best to make decisions in line with our values. The ACP guides our friends and family if we're in a situation where we can't speak for ourselves. It helps others to know what we want in our health care decisions instead of having to guess.

This guide was created to help you understand advance care planning. The guide walks you through each page and question of the ACP tool. We hope it will answer your questions as you complete it. Most importantly, you can change your plan at any time. Life changes and so may your wishes for care. You are not making decisions today — you are thinking about what would be important to you (or someone else) if you become very sick and can't speak for yourself.

SCENARIO 1

Jessica has had bad experiences in hospital and said her friends are not listened to or respected. She had friends who died in hospital without anyone being told they were there and she didn't want that to happen to her. She decided to bring her friends together to do advance care planning. They talked about who they would want to be part of their care if they were sick, their fears about sickness and dying, and what they would want to happen to their belongings and pets if they couldn't look after them anymore. Over a couple of weeks, she wrote down her thoughts on an Advance Care Plan (ACP) and shared a copy with her trusted friends. Jessica gave a copy to her doctor and asked them to put it on her medical record. Talking about and writing these things down gave Jessica a sense of relief and power knowing that the medical system has to take her wishes seriously.

GETTING STARTED

Advance care planning is a process. Some people complete the plan in small bits at a time rather than all at once. Questions can be answered in any order. Some people complete their ACP alone, while others find it helpful to do it with friends or workers they trust. If you are supporting someone to complete their ACP, please know that this is not just another form to fill out – it is a document that can ensure that people’s values and wishes are respected. Advance care planning conversations are important at any stage of one’s health journey.

After you’ve finished the ACP, keep it in a place where others can find it. You can give copies to the people you named on the first page, and others such as family, friends, and workers involved in your care. You can also ask your health clinic or housing provider to keep a copy for you!

We’ve done our best to explain ACP in this User Guide, and we’d welcome your questions and comments about anything you find confusing or unclear. We want this to be useful, and we want to be sure that you get your questions answered. Please contact equitableaccess@uvic.ca.

SCENARIO 2

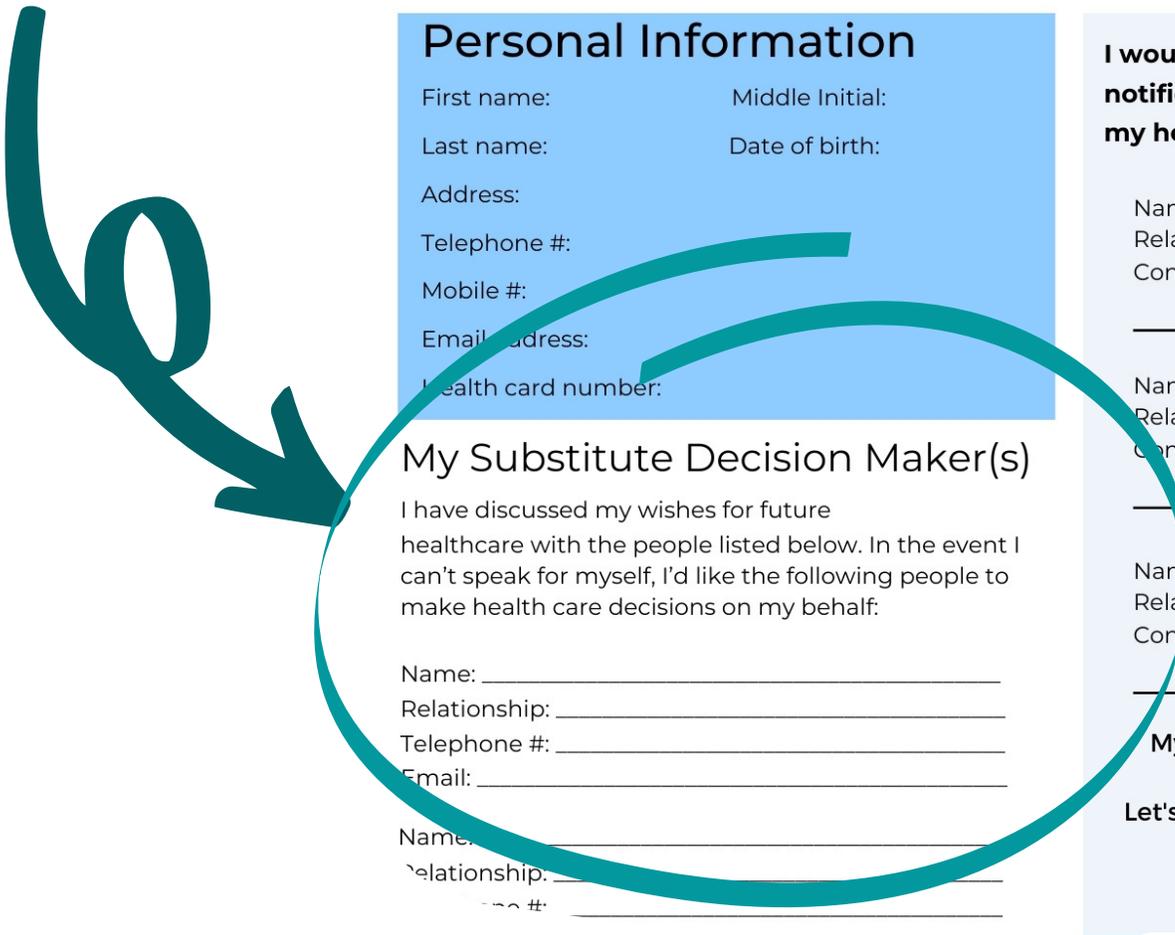
During an intake into transitional housing, Jonah filled out an Advance Care Plan (ACP) with his housing worker. A few months later, he had an accident and wound up in hospital in a coma. While going through his wallet to look for ID, the hospital social worker found the ACP card saying that Jonah had an ACP in the community. They called his housing provider who faxed over the ACP and called the people that Jonah had named in his ACP – who he wanted notified if his health changed significantly. Jonah’s friends showed up at the hospital and because they had copies of the ACP, were able to support him in line with his wishes. For instance, Jonah had written that he wanted to listen to rock music and so his friends set up a radio for him. The transitional housing staff kept his belongings safe and secure while he was in hospital and felt good that they knew who to reach out to. Jonah recovered and moved back into transitional housing feeling good that his friends were notified, his belongings were kept safe and secure, and that the hospital staff listened to his wishes.

UNDERSTANDING PAGE 1

This is where you write names of people who are in your circle of care. Your circle is made up of people you trust when you need help. They are the people you want by your side when the chips are down and tough decisions need to be made.

Your **Substitute Decision Maker** is someone who makes decisions for you if you cannot speak for yourself. This is an important role and it's best if it's someone who knows you well and cares about you personally. They should know your wishes for healthcare so they can advocate for your interests based on what you wrote in your ACP.

If you don't name a decision maker, the health care system will identify a **Temporary Substitute Decision Maker** by contacting (in order) your spouse, child, parent, sibling, grandparent, grandchild, anyone else related by birth or adoption, close friend, or a person related by marriage. There are many reasons why it may be important to name a substitute decision maker, for example if you don't have connections or good relations with your biological family. For more information, please visit: www.equityinpalliativecare.com



Personal Information

First name: _____ Middle Initial: _____
Last name: _____ Date of birth: _____
Address: _____
Telephone #: _____
Mobile #: _____
Email address: _____
Health card number: _____

I would like the following people notified if there is a significant change in my health:

Name: _____
Relationship to me: _____
Contact Information: _____

Name: _____
Relationship to me: _____
Contact Information: _____

Name: _____
Relationship to me: _____
Contact Information: _____

My Substitute Decision Maker(s)

I have discussed my wishes for future healthcare with the people listed below. In the event I can't speak for myself, I'd like the following people to make health care decisions on my behalf:

Name: _____
Relationship: _____
Telephone #: _____
Email: _____
Name: _____
Relationship: _____
Telephone #: _____

My life matters and I want to be sure my wishes are known. These are my wishes. Let's make sure people know what is important to me.

UNDERSTANDING PAGE 1

I have also discussed my wishes with the following people/care providers:

Name: _____

Relationship: _____

Contact info: _____

They have a copy of my care plan

Name: _____

Relationship: _____

Contact info: _____

They have a copy of my care plan



On the right column is an area to write down the contact information of the people you wish to be contacted if your health changes significantly, for example, if you are admitted to hospital or if you receive a life-threatening diagnosis.

Finally, signing and dating the form in the lower right corner will give permission for anyone listed to be allowed to see your ACP. This ensures that the people who are caring for you are all on the same page about how to make decisions that align with your wishes.

Right below the Substitute Decision Maker section is a space to write down the names of other people who know about your wishes. This section can include friends, family, caregivers, health care providers, and social workers. You may also choose to tell your nurse or doctor about your ACP and give them a copy to include in your health record which can help providers in the health care system work together to honour your wishes.

Name: _____
Relationship to me: _____
Contact Information: _____

Name: _____
Relationship to me: _____
Contact Information: _____

Name: _____
Relationship to me: _____
Contact Information: _____

My life matters and my death matters.

These are my choices.

Let's make sure people who care about me know what is most important.

I consent to the release of the personal information contained in this Advance Care Planning Document by any person named in this document and by any person providing social, medical or healthcare services to me, for the purposes of providing those services or achieving my wishes.

Signature: _____

Date: _____

UNDERSTANDING THE QUESTIONS

QUESTION 1 ASKS WHAT YOU VALUE MOST IN TERMS OF YOUR MENTAL AND PHYSICAL HEALTH.

My Wishes for at End of Life

1. What do I value most in terms of my mental and physical health? If I became ill, would I want to live as long as possible? Would I want to avoid machines and medical procedures that keep me alive, but don't make my life better? Other examples: having my pain be in control, making connections with my chosen family, etc.

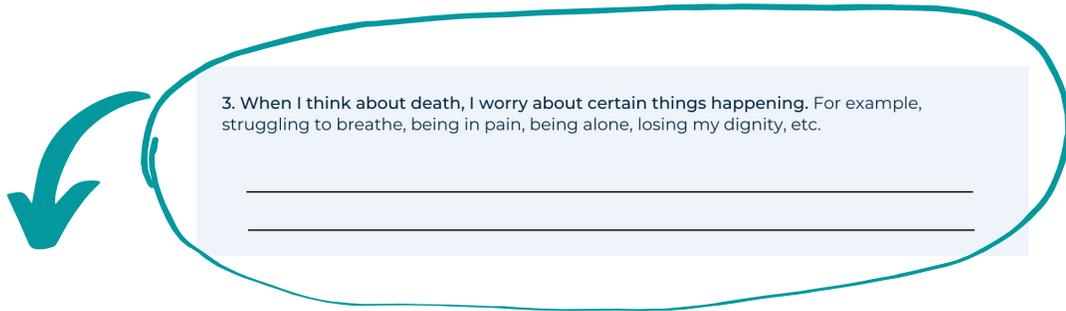
Values are the things that are most important to us. Here, think about what you most value about your mental and physical health. For example, if you became very ill, would you want to live as long as possible? Would you want to avoid machines and medical procedures that keep you alive, but don't improve your life? What would you want your care team to know about you and your wishes for your ongoing medical care? What is important to you? We are not asking you to make these decisions today – we are talking about what would be important to you if you were very ill so you and your friends and family are prepared.

2. What abilities are so critical to my life that I can't imagine living without them? For example, being able to live on my own, being able to communicate, not wanting to use substances, etc.

QUESTION 2 ASKS YOU TO THINK ABOUT WHAT ABILITIES ARE SO CRITICAL TO YOUR LIFE THAT YOU CAN'T IMAGINE LIVING WITHOUT THEM.

For some people, it is really important to be able to do things for themselves like going to the bathroom or being able to walk or feed themselves. Some people want to continue to use drugs and/or alcohol, or to keep living where they are living. Sometimes when we are very ill, we can't always do the things we want. But knowing what is critical to your life can help your friends and family and the care team know what is most important to you.

QUESTION 3 ASKS YOU TO CONSIDER WHAT YOU WORRY ABOUT WHEN YOU THINK ABOUT DYING OR DEATH.



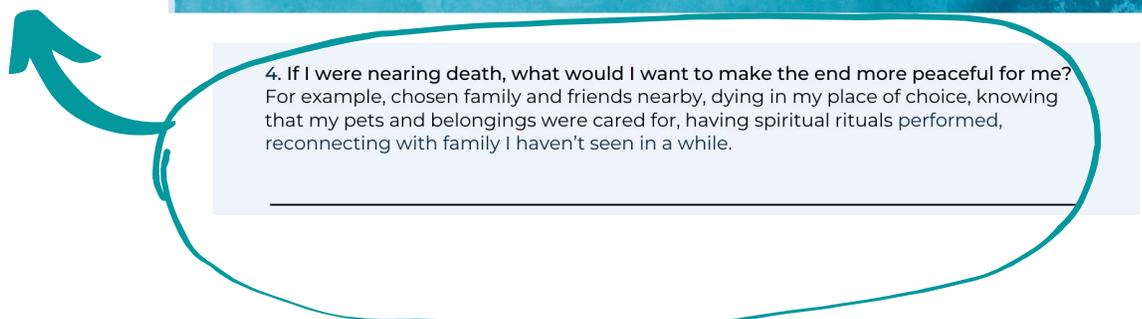
3. When I think about death, I worry about certain things happening. For example, struggling to breathe, being in pain, being alone, losing my dignity, etc.

We don't like to think about dying, especially when we are well. But, to live and die well, we need to plan well. Understanding what you worry about when you think about dying can help us to plan how to meet your needs in ways that respect you and your wishes. Your worries could include physical things like being in pain, having trouble breathing, or feeling sick to your stomach. Or, you could be worried about going into the hospital or being alone when you are sick, or not being able to pay your rent or support your kids. You might be worried about who will look after your pets or your belongings. Write down what most worries you when you think about dying or death.

QUESTION 4 INVITES YOU TO THINK ABOUT WHAT YOU WOULD NEED TO MAKE LIFE MORE PEACEFUL FOR YOU WHEN YOU ARE NEARING DEATH.

Here are some ideas: favourite types of music (or types you can't stand!), comfortable room temperature, having family or friends nearby, special blankets or clothing (e.g. warm socks or do you prefer bare feet?), books or movies or TV, tasty foods or drinks, access to a phone or the internet, ability to use substances of your choice, or personal items that bring you comfort or have special meaning.

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4. If I were nearing death, what would I want to make the end more peaceful for me? For example, chosen family and friends nearby, dying in my place of choice, knowing that my pets and belongings were cared for, having spiritual rituals performed, reconnecting with family I haven't seen in a while.

QUESTION 5 ASKS YOU TO THINK ABOUT ANY SPIRITUAL OR CULTURAL PRACTICES THAT MIGHT AFFECT YOUR CARE DURING THE FINAL PHASE OF YOUR LIFE.



5. Do I have any spiritual or cultural practices that affect my care at the end of life? For example, beliefs about the use of certain medical procedures, connection to Indigenous elders and ceremonies, special consideration for my care?

For some people, this aspect of life may become more important as they come closer to death. For example, religious affiliations, ethnic identity, last rites or other end-of-life rituals, Indigenous ceremony, spiritual care leaders or counsel (e.g., priest or elder), or caregivers who speak your language of origin. Important: please note any religiously-based constraints to your medical care such as no blood transfusions.

QUESTION 6 OFFERS YOU SPACE TO INCLUDE ANY OTHER WISHES OR THOUGHTS YOU HAVE ABOUT THE END OF YOUR LIFE.

Is there someone special you'd like to have close by at night or when you're feeling especially lonely? If you want visitors, what's the maximum number you'd accept at one time? Do you have favourite poems or stories or quotes that someone could read out loud for you? Is there music you'd like to hear even if you're unconscious? Is there anyone you do not want to be present? Are there things you don't want (e.g., certain foods or other items)?



6. Other wishes and thoughts about end of life or after death planning. Write down anything that would help others understand and support your wishes.

QUESTION 7 IS FOR YOU TO CONSIDER AT LEAST THREE THINGS THAT YOU WANT TO DO BEFORE YOU DIE.



This may help your friends, family and care team know whether they can help you meet your wishes while you are still alive, or to decide whether medical treatments, if successful, would make it possible for you to fulfill your wishes.

7. Three things I want to do before I die:

QUESTION 8 FOCUSES ON THINGS THAT WILL HAPPEN AFTER YOU DIE.

Mostly we don't want to think about what happens after we're gone, but it's really helpful if we share our wishes with the people we leave behind. This can include your hopes and plans for your body, your pets and belongings, and how you want to be remembered.

8. Other things to think about:

What are my plans for my belongings? Where possible, include full names, chosen names, and contact information (use the next page if extra space is needed).

HERE ARE SOME QUESTIONS TO HELP GET YOU STARTED:

- Do you want to be an organ donor?
- Would you prefer cremation or burial? If you choose cremation, who should receive your remains?
- Do you have pets? What care will they require? Who will take care of them?
- Do you have belongings you wish to give? If so, please write the person's full name, chosen name, and how their contact information.
- Are there ways you want to be remembered? For example would you like a party in your honour, or a small group, or just with one close friend? Would you like to have an obituary published? Would you like a donation in your name?

The last page of the ACP tool provides extra space for you to answer these questions.

ABOUT OUR WORK

The ACP tool and guide is informed by research conducted through the Equity in Palliative Approaches to Care (ePAC) collaborative (www.equityinpalliativecare.com) aimed at improving access to quality care for people facing the end-of-life and who also face inequities due to homelessness, poverty, isolation, racism and stigma. These tools were developed in collaboration with our Inner City Action Team, the ePAC Crew, and the Palliative Outreach Resource Team (PORT).

The need for advance care planning became clear when workers and street family witnessed their peers, clients, and loved ones in hospitals and other healthcare settings, unable to speak for themselves, and without having their wishes documented. Without this planning, caregivers were unprepared to deal with the questions that were coming up. Or maybe they had talked informally but didn't write down their wishes for tough end-of-life choices.

Too many times people who lived or worked in the street community didn't think about advance care planning until it was too late. Even if they had, ACP tools were not available or adapted to their unique situations. Our intent with these tools is to expand who is included in ACP conversations. This ACP tool and guide are informed by a review of the BC Ministry of Health's "My Voice" document and other publicly available tools.

THE CONSULTATION CONTINUES: WE WANT TO HEAR FROM YOU!

We want to ensure that our ACP tool and guide reflects the priorities of people who are using it. There's always room for improvement so we want to hear from you about whether it's meeting your advance care planning needs. What do you find most helpful? What improvements can we make? Please tell us by contacting equitableaccess@uvic.ca.