

Advance Care Planning

Making Your Personal and
Medical Wishes Known



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Advance Care Planning

Making Your Personal and Medical Wishes Known

Introduction

At Nova Scotia Health Authority (NSHA), we strive to offer care that respects your values, beliefs, and care preferences. Sometimes patients are not able to express their care preferences, but that does not mean their wishes have to go unknown.

This guide explains the process of advance care planning. This process can include an important tool called a personal directive (PD). You can use a PD to make sure your wishes and preferences will guide your care if you are unable to speak for yourself.

For a short video about personal directives, visit: <https://vimeo.com/142670928>



Take your time going over this information. People often find this topic uncomfortable to think and talk about, or feel that it isn't the right time to talk about it. This is normal. However, most people feel a sense of relief when they complete a personal directive. It can be a gift to themselves and their loved ones. A personal directive will help your loved ones to understand and honour your wishes at a critical, but difficult time. If you don't complete a directive, talking with your loved ones about what you would want can still be a help.

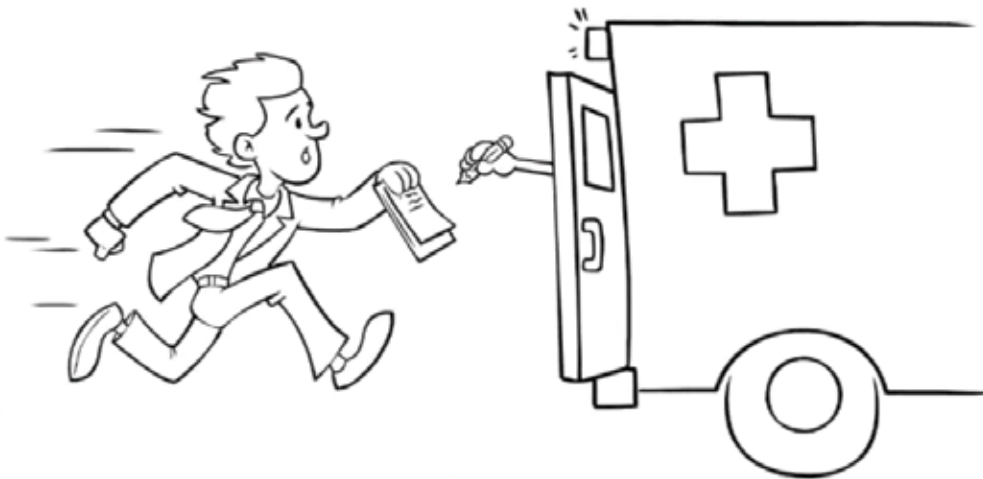
What is advance care planning?

Advance care planning is the process of reflecting on what is important to you to help you plan ahead for your future medical and personal care.

This process usually includes:

- Reflecting on what quality of life means to you
- Talking to your loved ones about what is important to you and your goals of care
- Talking with members of your health care team
- Learning about different treatments often used during emergency and end-of-life care
- Making decisions about your care goals
- Communicating your decisions verbally and in writing

The goal of this process is for you and your loved ones to be better prepared to make decisions about the kind of care you want to receive. It is a good idea for people of all ages and health situations to do advance care planning. Situations where you are unable to make decisions about your health care can happen to anyone at any time.



It is easier to plan in advance and make decisions about your preferences when you are home and feeling well, rather than in the middle of a medical crisis.

What is a personal directive (PD)?

A personal directive (PD) is a document that makes sure your care wishes are known when or if you cannot speak for yourself.

A PD can include:

- › Who you want to make decisions for you
- › Any treatments you are sure you would not want
- › Your beliefs and values about life and death
- › What quality of life means to you
- › Your hopes for care when you are at the end of your life
- › Other preferences about your personal care or related topics

This guide includes the PD form that is used at NSHA.



What is a delegate?

A PD lets you name an adult who must make sure your wishes are respected. They will also make care decisions for you if you cannot do so yourself. This person is called your delegate.

Naming a delegate in your PD makes it more likely that your wishes will be understood and followed.

It is important to check with the person you choose and talk to them about your PD. This will make sure they understand your wishes and are willing to act as your delegate.

To avoid a conflict at the time of decision-making, only name one person as your delegate.

You can choose an alternate delegate in case your delegate is unavailable. You can also name anyone else you wish to be part of making decisions about your care.



What if I don't have a PD?

If you are unable to speak for yourself and you do not have a PD, your health care team will look for your nearest relative to make decisions for you. This relative is chosen from a list that starts with a spouse or common-law partner, then children, then parents, and so on. The person chosen from the list needs to agree to speak for you and also needs to have been in contact with you in the last year. If no one can be found, a public trustee will be assigned to be your decision-maker.

For many people, the person that is chosen based on the list is the person they would want making decisions for them. This is not the case for everyone. It is best to choose your delegate and name them in a PD to make sure that the person you want to speak for you is the person who does so. Not only will your delegate be prepared to speak for you, they will also have a better idea of what your wishes would be in different situations.

Are there different ways to complete a PD?

There are 3 types of PDs:

1. Delegate – names the person(s) you want as your decision maker(s)
2. Instructional – records your care preferences
3. Combination – includes both Delegate and Instructional

A combination PD is the most complete, but any type of PD is helpful.

You can use NSHA's form or a different form, or write your own PD. You can also complete a PD with your lawyer. Many lawyers encourage their clients to make a PD when they make their will. No matter which way you complete your PD, in order for it to be a legal document, it needs to be dated and signed by you and a witness. The witness needs to be 19 years of age or older and **cannot** be your delegate or your delegate's spouse or partner.

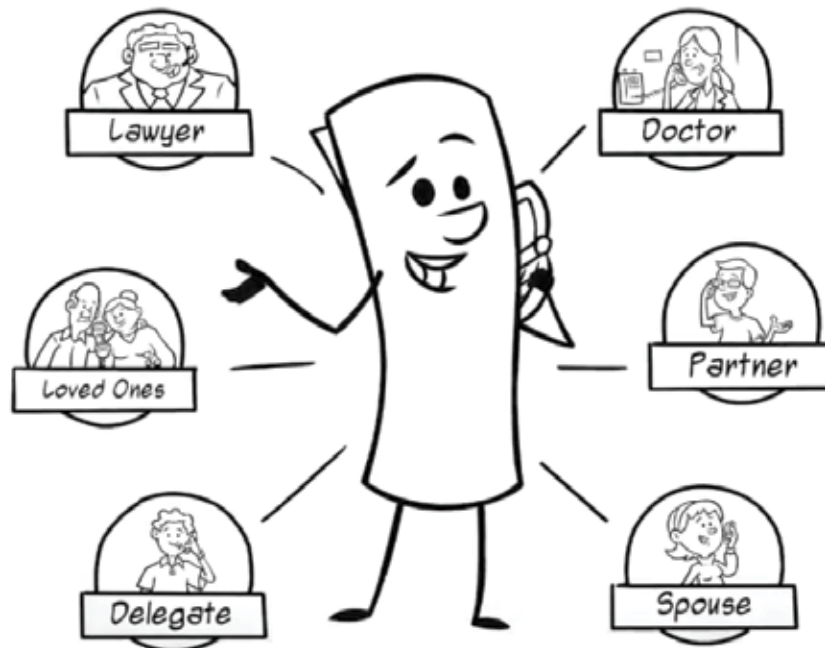


What should I do with my completed PD?

Once you have written your PD you should:

- Place a copy in a marked envelope on or near your fridge. This will make it easy for paramedics and your family members to find it if they need to.
- File the original somewhere safe.
- Give copies to your delegate(s) and anyone else who might be concerned about you during a health crisis.
- Give a copy to your primary health care provider.
- Give a copy to your lawyer, if you choose.
- Add it to your electronic hospital file by giving a copy to your specialist, bringing it with you if you go to the Emergency Department, or taking it to Medical Records (on the 5th floor of the Dickson Building at the Victoria General site, QEII).

You should also make a list of all the people and places that have your PD. If you decide to update it at a later date, you will want to collect the old copies and replace them with the most up-to-date version.

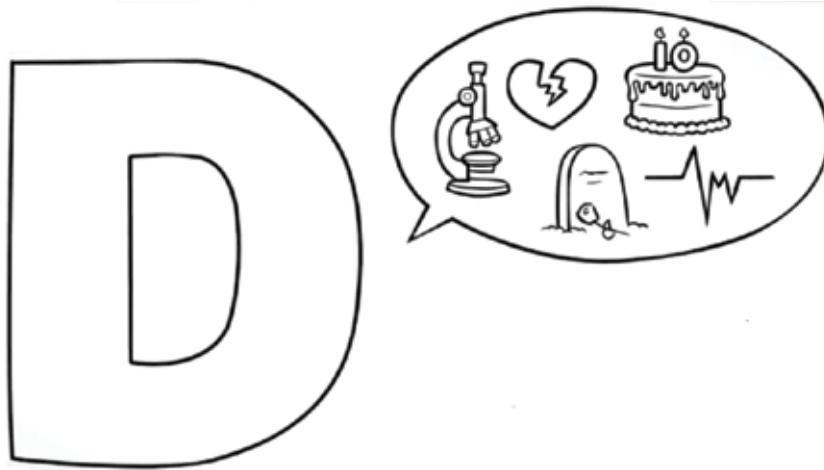


When should I update my PD?

It is important to consider updating your PD whenever there are changes in your life.

“The 5 Ds” are times when it is important to think about updating your PD:

- › Death of a loved one
- › Divorce
- › Diagnosis of a medical issue
- › Decline in general health
- › Decade (new decade on the calendar)



In each of these situations, the information you shared in your PD may change and you may wish to update your preferences. If you do update your PD, be sure to collect and destroy all old copies and share the updated version, with a current date, your signature, and a witness' signature.

What information and tools are available to help me?

On the next few pages you will find more information and tools to help you prepare for completing a PD. You do not need to use these tools, but they can be helpful when completing a PD.



Tool #1: Preparation questions

To prepare for completing your PD, you may wish to think about the following questions:

- What makes my life worth living?

- What are my beliefs about life and death?

- Do I value good quality of life over living as long as possible?

- What does quality of life mean to me?

- Is good pain control more important to me than being fully alert?

- What would it take for me to feel that life was no longer worth living?

- What are my experiences with death and dying? Have I known or been with anyone who was dying? What did I learn from those experiences?

- When I think about death and dying, what do I worry about most?

- What would a good death look like to me?

- If I needed ongoing daily care, what would I want my caregivers to know about me (what I like to eat, do with my day, do for entertainment, etc.)?

- Who do I want to speak for me if I cannot speak for myself? Would that person respect my wishes? Would they want to take on this role?

- Do I want to have a backup person (alternate delegate) to speak for me if my first choice is unable to?

Tool #2: Are some conditions worse than death?

This tool will help you think about situations where you might not want medical treatments that would keep you alive. Ask yourself what you would want in the situations below **if treatment would not reverse or improve your condition.**

Directions: Circle the number from 1 to 5 that best shows how you feel about these situations.*

- 1 — Definitely would want treatments that might keep me alive
- 2 — Probably would want treatments that might keep me alive
- 3 — Unsure of what I would want
- 4 — Probably would NOT want treatments that might keep me alive
- 5 — Definitely would NOT want treatments that might keep me alive

What if you ...		
1.	Can no longer get outside; spend all day at home	1 2 3 4 5
2.	Can no longer contribute to your family's well-being	1 2 3 4 5
3.	Are in severe (very bad) pain most of the time	1 2 3 4 5
4.	Are in severe discomfort most of the time (such as nausea [feeling sick to your stomach] or diarrhea)	1 2 3 4 5
5.	Are on a feeding tube to keep you alive	1 2 3 4 5
6.	Are on a kidney dialysis machine to keep you alive	1 2 3 4 5
7.	Are on a breathing machine to keep you alive	1 2 3 4 5
8.	Need someone to take care of you 24 hours a day	1 2 3 4 5
9.	Can no longer control your bladder or bowels	1 2 3 4 5
10.	Live in a nursing home	1 2 3 4 5
11.	Can no longer think or talk clearly	1 2 3 4 5
12.	Can no longer recognize family or friends	1 2 3 4 5
13.	Need to be sedated (given medication to sleep or relax) to control your pain	1 2 3 4 5

*This tool was adapted from the American Bar Association's Commission on Law and Aging from R. Pearlman, et. al., *Your Life Your Choices - Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*, Veterans Administration Medical Center, Seattle, Washington; www.elderguru.com/downloads/your_life_your_choices_advance_directives.pdf

What are some treatments I should consider when making a PD?

When making the decision on what treatments you may or may not want, it is first helpful to understand resuscitation. In a medical situation, resuscitation usually means that your heart or breathing has stopped and your health care team is trying to restart them. It may also mean that you are close to death and your health care team is trying to keep you alive. You have the legal right to refuse to start (withhold) or to stop (withdraw) resuscitative treatments at any time.

It is important to talk with your primary health care provider about how likely it is that resuscitation treatments might help or harm someone with your health condition(s). In general, if you have medical conditions related to your heart and/or lungs, the risks of resuscitation treatments are likely to be greater. These treatments are less likely to work or be helpful. You may also not recover fully to the quality of life you had before the treatment.

When deciding your wishes for resuscitation, consider how you feel about each of these options:

- **Comfort treatment** – you want to avoid any treatments that would resuscitate you or keep you alive if you were dying; you want only the treatments that will keep you comfortable until you die.
- **Selective treatment** – you want some treatments to be considered, but also want to avoid others.
- **Full treatment** – you want all treatments available to you to be considered, including full resuscitation.

When deciding which option is best for you, think about:

- › How healthy you are
- › How happy you are with your current quality of life
- › How happy you would be if your quality of life were made worse by a certain treatment(s)
- › How happy you would be if the outcome of a treatment would mean changes in where you live
- › Any experience you have had with death, dying or resuscitation treatments
- › How you feel about different treatments, especially resuscitation



Below is a list of treatments to consider, ranging from comfort treatment to full treatment, and the risks and benefits of these treatments. If thinking about this upsets you, you may want to take breaks as you read this section. If you are ready to think and talk about your care preferences, it is important for you to know what treatments may be involved. This will help you make decisions about your future care that reflect what is important to you.

Palliative Care

This is an approach to care that focuses on your comfort and quality of life when you have a progressive, life-threatening illness.

Palliative care teams support you and your loved ones by offering:

- › help to manage physical symptoms like pain, extreme shortness of breath, nausea, constipation, anxiety or agitation
- › help with emotional, mental or social distress
- › spiritual support services
- › a chance to deal with unfinished business
- › an opportunity to update your PD and/or goals of care documents
- › bereavement support for your loved ones
- › care in the place of your choice (e.g., at home, if you wish)



Choosing palliative care does not mean getting less care, it means getting the care that reflects what is important to you.

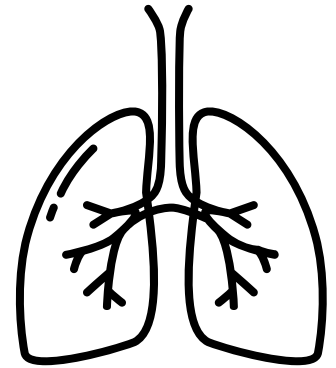
Intubation/Mechanical Ventilation

This treatment can be given when your lungs are no longer working. It is often called “life support.” With this treatment, your health care team will sedate you with medication and then put in a tube that goes in your mouth, down your throat, and into your lungs (intubation). This tube is connected to a machine (ventilator) that will breathe for you. Once the tube is in, you will not be able to talk or eat. You will be sedated until the tube is removed. The risks of this treatment include:

- › getting an infection in your lungs
- › injury to your throat and vocal cords from the tube

Intubation is not a long-term treatment. After 10-14 days, it can start to hurt the walls of your throat and mouth. At this time, if your decision maker and health care team decide to continue using a breathing machine for a longer time, you will need to have a minor surgery to put the tube into your lungs through your neck (tracheotomy) instead of your mouth and throat.

The goal of intubation is to support your breathing so that your body can rest while the underlying illness is treated. The hope is that your lungs will get strong enough for you to breathe on your own without the help of the ventilator. If you have lung disease, depending on the severity, it may be less likely that you will be able to breathe on your own after the tube is removed. This will mean you either die when the tube is removed, or you will need a ventilator to breathe for the rest of your life.



Some people feel that they do not want to risk having to use a ventilator indefinitely, or having their loved ones need to decide when to remove it. It is important to consider how you feel about intubation and make your preferences known in your PD.

If you decide you do not want intubation, there are other ways that your health care team can support your breathing. These treatments are less risky than having a tube go down your throat, but they may not be as effective. One example of this is non-invasive ventilation, or BiPAP (Bilevel Positive Airway Pressure). This treatment involves wearing a tight-fitting mask that helps you breathe by pushing air into your lungs.

If you decide you do want intubation, it is important to think about how long you would want the health care team to use this treatment and make this clear in your PD. Your health care team will usually have a good idea of whether continuing intubation will be helpful within 3-4 days. You can also state that you do not want intubation continued once your health care team has determined that it is unlikely you will return to a good quality of life. This will lower the chances of you living on life support. Making this known can also be helpful for your loved ones if they ever have to make the decision to remove you from this treatment. It can give them peace of mind to know they are choosing what you would choose.

Cardiopulmonary Resuscitation (CPR)

This treatment is done when your heart and/or lungs have stopped working or may soon stop working. It may include:

- Pushing hard on your chest to help your heart to beat (chest compressions)
- Someone breathing into your mouth, or putting a tube into your windpipe so a machine can put air into your lungs
- Giving electric shocks to your chest
- Giving you medications



CPR does not work the way it is often shown on TV. Common risks include:

- › broken ribs or chest bones
- › damage to the lungs
- › brain damage from lack of oxygen
- › skin burns from electric shocks to your heart
- › needing to be put on a breathing machine (ventilator)

Even if CPR works and your heartbeat and breathing are restored, there is a good chance you will suffer some or all of the effects listed above. The chances of CPR working on someone who has no major health issues is about 20% (1 in 5). For someone who is elderly, frail, and/or has heart or lung issues, the chances drop to less than 5% (less than 1 in 20). Most survivors from this group go on to die later in hospital, or need major adjustments to their living arrangements to support a higher level of care.

The goal of resuscitative treatments like CPR and intubation is that you live longer. Unfortunately, you may live with a lower quality of life. These are not easy choices to make. If you need help making these decisions, please talk with your primary health care provider.

Summary

Your PD should reflect your wishes as of today. Remember, you can update your PD at any time. Also remember that your PD will not be used unless you are unable to speak for yourself. If you are able to speak for yourself, you will make your own decisions about your care, as needed.

Once you have completed your PD and made it available to the right people and in the right places, you may have greater peace of mind knowing that your loved ones and health care team will be better able to understand and honour your wishes if you are not able to speak for yourself.

If you would like further support in completing a PD, you can contact your primary health care provider or your lawyer. You can also use the following list of resources to gain more information and to find other PD templates.

Resources

Personal Directives in Nova Scotia

- › <https://novascotia.ca/just/pda>

Speak Up – Advance Care Planning in Canada campaign

- › www.advancecareplanning.ca

Dying with Dignity Canada – Nova Scotia Chapter

- › www.dyingwithdignity.ca/nova_scotia

Advance Care Planning – MyHealth.Alberta.ca

- › <https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-topic-overview.aspx>

Advance Care Planning – Five Wishes® by Aging With Dignity

- › <https://fivewishes.org>

Start the Conversation – Vermont Assembly of Home Health and Hospice Agencies

- › www.starttheconversationvt.org

INSPIRED COPD Outreach Program™

- › www.nshealth.ca/content/inspired-copd-outreach-program



PERSONAL DIRECTIVE OF _____

If possible, I hope for the following:

Sample questions for consideration: How would I prefer to spend the last years (or months) of my life, if this is possible for me? How would I like my family, physicians and others who are important to me to respond/react to suddenly-developing health circumstances in which my life is threatened or ending? What would 'good death' look like for me, e.g., what are my preferences regarding where, and in what circumstances, my life ends?

I am **CERTAIN** I do not wish, under **ANY** circumstances, that the following treatments and/or interventions be used in my future care:

Other specific instructions or information (not covered above) that I wish my substitute decision maker (delegate or statutory decision maker), family and people who provide my personal care to be aware of (in addition to health care and treatment, personal care includes where I live; what I eat and drink; my clothing, hygiene, safety, comfort and recreational and social activities; and services in the community that support me):

Naming a Delegate

Complete the section if you wish this to be a combined delegate and instruction personal directive. If you do not name a delegate, this will be an instruction directive.

In circumstances in which I am unable to make personal care decisions on my own, I hereby designate _____, who is 19 years of age or older, as my delegate (substitute decision maker).

Address: _____

Telephone number(s): _____

Email address: _____





PERSONAL DIRECTIVE OF _____

Other Optional Content

If the above designated delegate is unable, unwilling or unavailable to make a personal care decision on my behalf, I authorize the following person to act as my alternate delegate:

Name: _____

Address: _____

Telephone number(s): _____

Email address: _____

A physician who is assessing my capacity to make personal care decisions on my own is to consult with:

Name: _____

Address: _____

Telephone number(s): _____

Email address: _____

My delegate or alternate delegate is to consult with the following person(s) when making decisions about my personal care:

Name: _____

Address: _____

Telephone number(s): _____

Email address: _____

This Personal Directive is made pursuant to the *Personal Directives Act*.

Dated and signed this ____ day of _____ 20 ____

Signature: _____ Print name: _____

Witness Signature: _____ Print name: _____

Address: _____

Telephone number(s): _____

Email address: _____



Looking for more health information?

Find this pamphlet and all our patient resources here: <http://library.nshealth.ca/PatientGuides>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

Connect with a registered nurse in Nova Scotia any time: call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

Nova Scotia Health Authority promotes a smoke-free, vape-free, and scent-free environment.

Please do not use perfumed products. Thank you!

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The information in this pamphlet is to be updated every 3 years or as needed.