

Advance Care Planning

Making Your Personal and Medical Wishes Known



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Advance Care Planning

Making Your Personal and Medical Wishes Known

At Nova Scotia Health, we do our best to offer care that respects your values, beliefs, and preferences. If you are not able to express your care preferences at the the time of receiving your care or treatment, that does not mean your wishes cannot still be followed.

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 not able to talk for yourself.

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



Take your time going over this information. You may find it uncomfortable to talk and think about this topic, or you may feel that it is not the right time to talk about it. This is normal.

But you may also feel a sense of relief when you complete a PD. It can be a gift to yourself and your loved ones. A PD will help your loved ones to understand and honour your wishes at a critical, but difficult time.

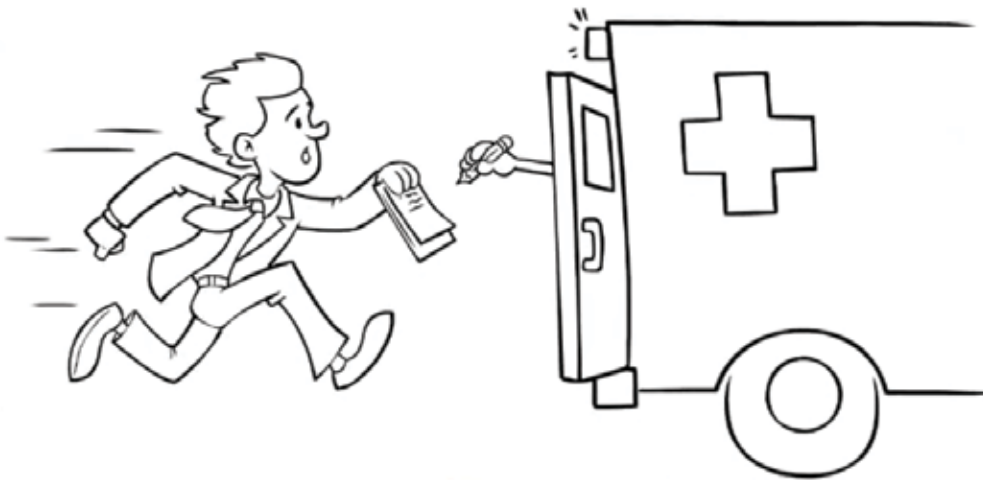
If you do not complete a PD, talking with your loved ones about what you would want can still help.

What is advance care planning?

Advance care planning, or personal care planning, is the process of reflecting on what is important to you, to help you plan 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 treatments often used during emergency and end-of-life care
- Making decisions about your care goals
- Communicating your decisions verbally (by talking) 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 not able 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 at home and feeling well, rather than in the middle of a medical crisis.

The following are definitions of words commonly used in advance care planning:

Health care decision – This is a decision about the prevention, examination, diagnosis, or treatment of a health condition. This also includes instructions, consent, and/or refusal and withdrawal of consent with respect to health care.

Health care provider – This is a person who is licensed or registered in the province to provide health care (like a family doctor or nurse practitioner, specialist, or nurse).

Personal care – Personal care includes:

- › a person’s health care and treatment
- › where they live
- › what they eat and drink
- › their clothing, hygiene, safety, comfort, recreational and social activities, and services in the community to support them

Treatment and interventions – The word “treatment” usually refers to a medication, drug, or therapy that is prescribed for you by a doctor. The word “intervention” usually refers to a procedure or device used in your health care, like electroconvulsive therapy (ECT) or cardiopulmonary resuscitation (CPR) (using medical instruments to restart your heart and help you breathe).

This means any examination, procedure, service, medical or other health care treatment that is done for a therapeutic, preventative, palliative, diagnostic, or other health-related purpose, and includes a course of health care or a care plan. Treatment includes but is not limited to: surgeries and procedures, administration of drugs or other interventions, and physical interactions with health care providers (like physical contact, venipuncture, or exposure to radiation) or verbal interactions with health care providers (like emotional support or psychological interventions).

What is a personal directive (PD)?

A personal directive (PD) is a legal document in which a person with capacity (see definition of capacity on page 5) sets out what, how, and/or by whom personal care decisions are to be made in the event that they are no longer capable of making these decisions on their own.

A PD must be in writing, dated, and signed by the person making the PD. If the person making the PD is not able to sign, the PD can be signed by another person in the presence of the person making the PD, as long as the person signing is not the delegate or the delegate's spouse. The PD must also be witnessed by someone other than the delegate (see page 4) or the delegate's spouse. The person signing on behalf of the person making the PD must not also be the witness.



A PD can include:

- What kinds of personal care you would choose or refuse
- The name and contact information for your delegate (if a delegate is named)
- A statement of personal values, beliefs, or goals that you wish to guide decision-making about your personal care
- The name(s) of a person(s) with whom the delegate is to consult in making personal care decisions
- The name of a person you may wish your doctor to consult when assessing your capacity to make a personal care decision on your own
- The names of people who are to be notified and not notified of the coming into effect of the personal directive.
- The name(s) of any near relative(s) or other relative(s) who is not to act as your substitute decision maker.
- Any other information you wish those who provide your personal care to have.

This guide includes the PD form that is used at Nova Scotia Health.

What is a delegate?

This is a person 19 years of age or older who is authorized (legally allowed) in a PD to make personal care decisions on another person's behalf when that person is not able to make these decisions on their own. Your delegate should be someone who knows you well, is willing to make difficult decisions even under stress, and whom you trust to speak and act for you.



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 are willing to act as your delegate and understand your wishes.

You may only appoint one delegate to make decisions for you at a time.

Joint delegates are not permitted and could make your PD invalid (not able to be used). It is acceptable to appoint more than one delegate in the following circumstances:

- Two (2) or more delegates may be appointed to make different types of decisions (for example, you may appoint one delegate to make your health care decisions and a different delegate to make all other personal care decisions).

OR

- You may appoint one delegate to make your personal care decisions, and one or more alternate (other) delegates to make decisions if the first delegate you appointed cannot, or is not willing to, act as your delegate. This person cannot be appointed to do both (cannot be jointly appointed).

You can also name anyone else you wish the delegate to consult with in making decisions about your care.

If you appoint a spouse as your delegate, their appointment will be revoked (taken away) if at the time your spouse is no longer your spouse — unless you specifically state in your PD that they spouse will continue to be the delegate even if they are not your spouse in the future.

Any person that provides you with personal care for compensation (paid employee) cannot be a delegate unless you specifically state in your PD that the personal care services that they have provided are paid and are specifically authorized by you.

Capacity – This is the ability to understand information that is relevant to a decision about personal care, and the ability to appreciate the reasonably foreseeable consequences (what will likely happen as a result) of the decision. With regard to health care and treatment, a person with capacity is able to understand:

- › The medical condition for which a treatment or intervention is proposed
- › The nature and purpose of the treatment or intervention
- › The risks involved in undergoing the treatment or intervention
- › The risks involved in not undergoing the treatment or intervention

A person 19 years or older, is believed to have capacity unless they are formally assessed as being incapable by an appropriate health care provider.

What if I do not have a PD?

If you are not able to talk for yourself and you do not have a PD, and there is no court appointed guardian/representative, 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 (married spouse/registered domestic partner/common law spouse), then children, then parents, and so on. The person chosen from the list must agree to talk for you and must also have been in contact with you in the last year, unless they are your spouse. The person chosen from the list must identify if there is a relative in a higher priority than them from the list and will have to sign a form declaring their agreement to act on your behalf.

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 this 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 talk for you is the person who does so. Not only will your delegate be prepared to talk for you, they will also have a better idea of what your wishes would be in different situations.

A delegate that you have appointed can make more types of decisions than the nearest relative. The nearest relative is limited to making decision on health care, accepting a placement offer in a continuing care home, or home care services.

You can use Nova Scotia Health'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 how a PD is completed, in order for it to be a legal document, it must be:

- In writing.
- Signed and dated by you.
- Witnessed and signed by a person who is 19 years old or older.



Where do I keep my PD? Who should have a copy?

- 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 health record by giving a copy to your specialist, bringing it with you if you go to the Emergency Department, or submitting a copy for your medical records. For help with this, email Health Information Services:

Central Zone: Authorization of Personal Health Information

› Email: APHI@nshealth.ca

Eastern, Western, or Northern Zone: Health Information Services

› Email : NSHAROI@nshealth.ca

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.

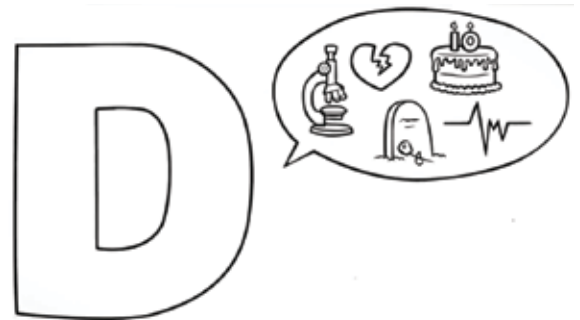


When should I update my PD?

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:

1. Death of a loved one
2. Divorce
3. Diagnosis of a medical issue
4. Decline (getting worse) in general health
5. Decade (new decade on the calendar)



In each of these situations, the information in your PD may change and you may wish to update your preferences.

You may cancel your PD by:

- Writing a new PD; or
- Providing a written statement signed by you stating that you wish to cancel (revoke) your PD; or
- Destroying your PD or directing a person to destroy it while in your presence.

You may change your PD by cancelling your PD as described above and writing a new one 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 get ready to complete a PD.

Tool #1: Preparation questions

To get ready to complete 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 talk for me if I cannot talk 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 talk for me if my first choice is not able 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 - Not sure 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 (like nausea [upset stomach] or diarrhea [loose, watery poop])	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 your family or friends	1 2 3 4 5
13.	Need to be sedated (given medication to relax or sleep) 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 deciding what treatments you may or may not want, it is 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, resuscitation treatments are likely to have more risks. 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 each. 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 (gets worse over time), life-threatening illness.

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

- › help to manage physical symptoms (like pain, extreme (very bad) shortness of breath, nausea, constipation (not being able to poop), 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 (grief) support for your loved ones.
- › care in the place of your choice (for example, at home, if you wish.)



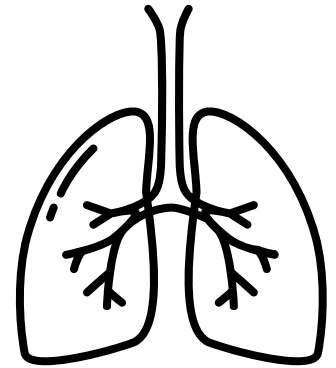
Choosing palliative care does not mean getting less care. It means getting the care that reflects what is important to you.

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. They will then put a tube in through 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 to 14 days, it can start to hurt the walls of your throat and mouth. At this time, if your delegate and health care team decide to keep 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 how bad it is, 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 (with no set end date), 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, 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 to 4 days.

You can also state that you do not want intubation continued once your health care team has determined that it is not likely you will return to a good quality of life. This will lower the chances of you receiving prolonged (ongoing) 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 medication(s)



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 not having enough 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. But 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.

Medical Assistance in Dying (MAID)

MAID is a process where a person who meets a number of criteria is given medications at their request by a qualified health care provider to cause their death.

Canadian law defines Medical Assistance in Dying (MAID) as:

“the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death”; or

“the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death”.

It is currently not legal to make an advance request for MAID in a personal directive. This may change in the future.

If you are thinking about MAID, or have questions about it, it is important to talk with a health care provider, like:

- › A Medical Doctor (MD)
- › A Nurse Practitioner (NP)
- › Another health care provider (for example, a pharmacist, nurse, spiritual care leader, and/or social worker)

They can explain your options.

If you do not have a primary health care provider, or you have questions about MAID, you can call and talk with Nova Scotia Health’s MAID Nurse Navigator:

- › **Phone (Halifax area): 902-491-5892**
- › **Phone (toll-free): 1-833-903-6243**

They can give you information about MAID and/or arrange for you to talk with a health care provider.

You can also access Nova Scotia Health’s pamphlet, *Medical Assistance in Dying (MAID)*:

- › www.nshealth.ca/sites/nshealth.ca/files/patientinformation/2229.pdf

Summary

Your PD should reflect your wishes as of today. Remember, you can update your PD at any time. Your PD will not be used unless you are not able to talk for yourself. If you are able to talk 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. This will come from 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 talk for yourself.

If you would like more 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 for more information and to find other PD templates.

It is very important to remember to bring your PD, or a copy of it, to the hospital with you.

Resources

Personal Directives in Nova Scotia

- › <https://novascotia.ca/just/pda>

Advance Care Planning in Canada

- › 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/HealthTopics/Advance-Care-Planning>

Advance Care Planning – Five Wishes® by Aging With Dignity

- › <https://fivewishes.org>

INSPIRED COPD Outreach Program™

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

PERSONAL DIRECTIVE OF _____

In this Personal Directive, I state my wishes and preferences for my personal care, including my health care and treatment, should the time come when I am unable to make personal care decisions on my own. In these circumstances, I request that the content of this personal directive be respected and followed by my delegate (or statutory decision maker, if a delegate has not been named below), family and people who provide my health care.

In circumstances in which I am unable to make personal care decisions on my own:

I request that the below-listed, deeply-held, personal values and beliefs be respected: Sample questions for consideration: What is most important to me in my life right now? Do I highly value living independently and making decisions for myself? What religious or personal beliefs/convictions (if any) do I hold about how my life should end?

The below-listed goals and priorities are to be followed in my (plan of) care: Sample questions for consideration: What is more important to me – the length of my life or the quality of the life that I am living? Is good control of my pain more important to me than being fully alert all of the time (or vice versa)?

If possible, I wish to avoid the following: Sample question for consideration: What health and life circumstances (if any) can I imagine myself being in where I would rather that my life end than I remain in these circumstances for a prolonged period of time?



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: _____



What are your questions?
Please ask. We are here to help you.

Questions for my health care team:

Looking for more health information?

Find this pamphlet and all our patient resources here: <https://library.nshealth.ca/PatientEducation>
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 promotes a smoke-free, vape-free, and scent-free environment.
Please do not use perfumed products. Thank you!
www.nshealth.ca*

*Prepared by: The INSPIRED COPD Outreach Program™
Reviewed by: Legal Services, Nova Scotia Health
Designed by: Nova Scotia Health Library Services*

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The information is not intended to be and does not constitute health care or medical advice.
If you have any questions, please ask your health care provider.

