Advance Care Planning Canada

NSHPCA
Nova Scotia Hospice Palliative Care Association

My Advance Care Planning Guide

Because my wishes matter.

This plan was created by: _____

I was helped by:
- ☐ My supportive decision maker
- ☐ _____
- ☐ _____
- ☐ _____

I last reviewed my plan on: _____

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During the process of developing this guide we found inspiration and guidance in many sources, too many to note. Where possible we have included citations and acknowledgements throughout the guide. Thank you for your inspiration and guidance.

This guide is **not a legal document** and **cannot be used to provide consent for treatments**. For more information, visit www.advancecareplanning.ca.

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1 About Advance Care Planning

In this section:

- Introduction
- Why Create a Plan?
- Advance Care Planning Stories
- How to Use This Guide

Introduction

Welcome to your Advance Care Planning Guide. By using this guide, you are taking an important step for yourself and the people who matter most to you.

Advance Care Planning (ACP) is the process of thinking about what matters most to you in your life and what that means for your health and personal care. ACP helps you share your wishes and preferences with the people who are important to you. When everyone knows your wishes and preferences, they can help make sure you get the care you want.

What are wishes and preferences? Your wishes are your desires, the things you might want for your health and personal care. Your preferences are the choices you would make for yourself. Sharing your preferences will help the people in your life know the choices you would make for yourself.

When someone expresses their wishes and preferences, they are exercising their right to legal capacity or to make a choice. The idea of what this looks like is evolving across Canada. The law is shifting to a more open and inclusive view of what it means for a person to be able to express their wishes and preferences. We created this guide to support this shift.

Everyone is entitled to the presumption of capacity. This means **you are considered to have capacity unless there are reasons to believe otherwise**. Having capacity means that you are able to understand the necessary information and impacts of a decision about your healthcare. Your capacity may change over time and based on the situation.

Legal capacity is about making decisions about your own life and having those decisions recognized and respected. Extra support can enable people to exercise their legal capacity, this is called supported decision making.

For more about your rights and the legal requirements for planning for your future care, visit www.advancecareplanning.ca.

Knowing and expressing your wishes and preferences will look different for each person. You may also find your wishes and preferences change based on different situations. This guide will help you explore and identify your wishes and preferences and then share them with the right people so that you get the care you want.

This guide is for people across Canada, of all abilities. It is for people in good health and those who have health needs. This is a comprehensive guide. It may seem long but we have given you lots of space to add in your thoughts and **you get to choose how you use it**. Start where you want. Do the parts that make sense for you and for where you are in your journey. Draw pictures and write notes. You can use this guide on your own or with the support of others. The guide is here to help you through the planning process and with making a record of your plan.

If you are ready to start your advance care planning journey then you are in the right place.

Why Create a Plan?

Advance care planning (ACP) is part of life planning. Life planning involves financial planning, legal planning, health and social services, and community networks. ACP is an important step in taking control of your healthcare journey.



Advance care planning is a process, not just a document. This process will take time and is about thinking about what matters most to you and talking with the people who are important to you. You can make a plan on your own or with someone you trust. Sometimes people like to do their planning with a community of people. Making a plan with a larger group can make it feel less scary.

Advance Care Planning helps you to:

- **Think** about what is important to you
- **Learn** about the care you want
- **Choose** decision makers that you trust
- **Share** your wishes and preferences so the right people know what you want
- **Record** your preferences and decision maker(s)



What is a decision maker? Sometimes a decision maker(s) may be someone who needs to act temporarily as your substitute decision maker if you are ever unable to express your preferences yourself. In other instances you may need a decision maker to support you in expressing your wishes and preferences. A **substitute decision maker** can be the same person as a **supportive decision maker**, but they can also be different people.

"**Supported decision-making** is when someone needs help to understand and/or express their decisions. People may have friends, family, community members, or professionals help them express their choices. This support can enable people with various barriers to express consent and make care decisions rather than relying on a Substitute Decision Maker or Guardian."

- from the Pan Canadian ACP Framework

Remember, your plan **should** change as your life changes. Make sure you **review** and **update** your plan every 1-2 years or after any big life milestone such as getting married or a serious illness. You are in control and can change your plan at any time. Make sure you share any changes with the right people.

You should update your advance care plan regularly, just like you would change the batteries in a smoke detector, update your will or look at your savings plan.

Advance Care Planning Stories

Stories can help to build understanding and meaning. Here are a few stories that share some interesting planning experiences.



Salome's Story



Salome is a 79-year old Inuk woman, who lives in a rural, isolated community in Northern Canada. She has had many chronic health issues over the years. She was most recently diagnosed with heart failure.



Salome had designated her husband to make healthcare decisions on her behalf if she was no longer able to, but he recently died. Thankfully she has a large family for support, including 11 children, who are all actively involved in her life and her care.



Salome has some major health concerns and wants to avoid any conflict between her children if her health deteriorates further. She appoints her eldest daughter, Sophie, as her decision maker. Salome is confident that Sophie will honour her wishes and healthcare preferences, and make sure that the cultural aspects of her care are at the forefront.



As is her tradition, Salome decides to get all her family together for a meal to share her wishes and preferences.

Olívio's Story



Olívio is a 39-year-old man who was born with a condition that has affected the feeling in his legs. Olívio needs to use leg braces to walk and has lived with chronic pain his whole life. Olívio has surrounded himself with family, friends, and allies in the disability community.



Olívio has always told people that being in control of his own decisions and choices is really important to him. But Olívio wanted to be sure that all of his family, friends and allies have the same understanding about what he wants. So, recently he worked with one of his friends to create an Advance Care Plan.



When it came time to pick a decision maker, Olívio thought about asking his Portuguese-speaking parents. But, he worried that their language might become a barrier in an emergency. For this reason, Olívio asked his close friend Jean to be his decision maker.



Olívio and Jean met through a support group. They bonded over their similar experiences and challenges. They are comfortable talking openly about their values, wishes, and preferences. There is a deep understanding and connection between the friends. Olívio is confident Jean will help him to advocate for what he would want if he was ever unable to express his own wishes and preferences. Olívio thinks Jean will have compassion and be thoughtful of his needs.



Ajit's Story



Ajit came to Canada from India 2 years ago. Ajit's cousin Dalip came to Canada 7 years ago. He is Ajit's only relative here. They lead very different lives, but both value their shared ties to family, faith, and culture.



Ajit enjoys his work as a support worker and is improving his English through evening classes. Ajit met his friend Moraa, another newcomer, at an English class. She introduced him to her circle of friends and her support has helped Ajit to build his new life.



Through his work Ajit can see how important it is to plan for your future care. He has helped the families he works with share with their healthcare team what their loved ones want. Ajit understands that when families know what their loved ones want they can make better care choices for them.



Ajit decides that he should make an advance care plan for himself to make sure that those people who are closest to him know what he wants. After thinking about what he wants he asked himself who he would trust to make healthcare decisions for him if he couldn't make them himself. Moraa is important to Ajit in Canada. But, he would want the person making healthcare decisions for him to be connected to his family, faith, and culture.



Ajit chooses to ask his cousin to be his decision maker. Ajit invites Dalip to come over for lunch so that they can talk about healthcare choices and what matters most. Ajit feels good and knows that Dalip will make the decisions he would make.

Eloise's Story



Eloise is 18 years old and lives with her mother and father. Eloise was born with Muscular Dystrophy which has affected her ability to walk and speak. She uses a communication device to share her wishes and communicate with those around her.



Eloise's mother is her primary support person and often acts as her supportive decision maker, making sure that the doctors know what Eloise wants. Eloise dreams of being an author and writing fantasy books that feature people with disabilities.



Eloise's mother would like to make sure that Eloise's wishes are clear for everyone, and Eloise agrees this is a good idea. They use the ACP Guide to support their planning journey. Eloise asks her mother and father to be her supportive and substitute decision makers. She writes a story and shares it with them. Her story is about her desire to be an author and how her ability to share stories brings meaning to her life.



Shortly after completing her plan Eloise has an episode. She struggles to breathe and becomes unconscious. Her parents rush her to the hospital. The doctors recommend that Eloise be given oxygen support long term. Eloise's parents ask about the side effects of the treatment and evaluate all of the possible outcomes. Knowing that cognitively Eloise will still be able to write and use her communication devices they decide to go ahead. Eloise is fitted for respiration support, regains consciousness, and returns home within a few days.

How to Use This Guide

This is your planning guide. Make notes in it, highlight parts that you think are important, and add pictures. Advance Care Planning is a process, but you can **choose your own path**. You can answer the questions from start to finish. Or start where you feel comfortable. Use this guide how you want and make it your own.

Once you have completed this guide, you can print or save the “record” pages as a record of your ACP. Just remember that you will need to learn about the legal considerations that are specific to where you live.

Some provinces and territories will require you to complete legal forms to identify your “decision maker”. The legal considerations differ across Canada. Find out more about the requirements in your province or territory by visiting www.advancecareplanning.ca.

This guide is not a legal document and cannot provide consent for treatments.

Here are some suggestions for how you can use this guide:

- Complete the **My Values & Wishes** activities to help you reflect on your wishes. These activities will help you think about what matters most to you.
- Use the **Recording My Wishes** activities to make a record of your wishes and preferences and decide where and how to store your ACP plan.
- Use the **Support Network** activity to identify the people who you trust and look to for support.
- Use the **Choosing My Decision Maker** activity to help you choose who should be your decision maker(s). Knowing who the right people are will help both you and them feel confident.
- Use the **Sharing My Wishes** activities to plan how you will share your wishes and preferences with your support network and decision makers.
- Use the **Next Steps** to learn more about legal considerations and keeping your plan up to date.

2 My Values and Wishes

In this section:

- Learning About Values
- Activity
  What is Most Important to Me
- Turning Values into Wishes
- Activity
  What Matters to Me for My Care
- Recording My Wishes
- My ACP Record
  My Wishes and Preferences
- Jane's Journey

Learning About Values

In this section, we ask you questions that will help you think about the things you value. Values are the things you believe. Wishes are the things you desire for yourself. Your values guide important decisions in your life. While life is always changing, your values are likely to stay the same.

Take a moment to think about each question in this activity. There is no rush. You can do this alone or with people that support you.

Activity
What is Most Important to Me

- What does a good day look like for you? What do you like to do througout your day?

For example, being with my best friend and buying yarn. Then, we catch up over coffee and a gooey cinnamon bun.

- Who would you spend time with?

For example, my favourite niece, Suzy and my sister Anika.

- What would you most look forward to doing on a good day? Are there activities, hobbies, experiences or relationships that make you happy?

For example, walking along the local river and feeding the ducks or volunteering at my local community centre, I like being outside and being by myself but I also like helping people.

- What do you most look forward to at the end of your day? Are there activities that help you relax?

For example, reading a good book, with a warm blanket and my favourite music playing on the radio.

- What (or who) do you turn to when things are hard?

For example, I always go to my sister, Jill. She is my biggest supporter.

- Do you have any spiritual or religious beliefs or traditions that add meaning to your life?

For example, I find comfort in prayer and meditation.

- What is the most important part of these beliefs and practices for you?

For example, the cultural festivals and ceremonies. The colours, the sounds, the smells are all so exciting.

- How have these beliefs and traditions shaped your choices in the past?

For example, they connect me to my history and my family. They guide me to think about others and be kind.

Now look at what you shared. What stands out to you? The things that you have thought about here are probably the things you value most. Use these next questions to help you think about your answers and identify your values.

- When you look at your answers, what do you see?

For example, my friends, reading, being active, quiet time to think and being part of my community.

- Are there other things that matter to you that you have not added?

For example, being able to take care of myself.

- Are there any other traditions that are important to you?

For example, I like to celebrate with my adopted family every year on their birthdays.

- Is there anything else you want to add?

For example, my dog is my best friend, and I always want him taken care of.

Turning Values into Wishes

Now that you have thought about your values, let's see how they connect to your wishes and preferences.

We asked you questions about what matters most to you in your day-to-day life. Now we want you to think about what would be most important for you if you were to get sick. We want you to think about the care you would want.

It can be hard to think about what matters most for your care. This is because every situation is different. You might find that you are answering 'it depends' a lot. When you think about these questions, try to think about these common situations:



How would you feel if:

- You had to go to the hospital for an emergency?
- You became very sick and had to choose between two different but difficult treatments?
- You might lose your memory or ability to express yourself?
- You might lose any mobility you have or the ability to move around on your own?
- You would no longer be able to do your favourite thing?

Always remember, your answers can change. Your wishes and preferences may change as your life, feelings, and thoughts change. For now, answer the questions in the next activity based on how you feel today.

At the end of this section we will help you pull your values, wishes, and preferences together. It’s important to remember that although a change in ability might feel hard, people do adapt and you might not feel the same about a disability once you have lived with it for a while.

Activity
What Matters to Me for My Care

If you were ever to get sick:

- How much would you want to know about how sick you are and what's going to happen?

nothing — some — everything

Can you share why?

- Would your answer change if you were unlikely going to get better?

no — maybe — yes

Why do you feel this way?

Do you find pain hard to handle?

Pick one:

○ Yes ○ It depends ○ No

Can you share more about why?

How much do you value your privacy?

○ ——— ○

A little A lot

Can you share why?

How much do you value your ability to move around when and how you want?

○ ——— ○

A little A lot

Why do you feel this way?

- What would make it feel more enjoyable if you were not able to move around when and how you want?

For example, I would want to be able to draw and read.

- How would you feel if you were not able to express yourself, hear other people, or share your thoughts?

- ○ Terrified
- ○ Unhappy
- ○ Angry
- ○ Fine
- ○ Frustrated
- ○ Other

- If you couldn't express yourself with words, how else would you want to share your thoughts?

For example, I would like to paint or draw

- Are there people you would trust who can help to interpret your body language or mannerisms?

  Pick one:

  ○ Yes ○ It depends ○ No

  Could you share why and who?

- Are you comfortable with asking for help?

  Pick one:

  ○ Yes ○ It depends ○ No

  Could you share why?

- What kind of support would you like to be given now, or in the future?

For example, I would like help with getting in my wheelchair and sharing my ideas.

- Are there any things you do to take care of yourself or other types of care you use to support your well-being? For example, do you see a naturopath or chiropractor, or do you do yoga or meditate?

For example, I have a naturopath that I have been seeing for 10 years.

Did you want to add anything about why this is important or works for you?

Recording My Wishes

You have learned about your wishes and preferences and now it is time to make a record.

It is important to make a **record** of your wishes and preferences. Making a record means that everyone has access to the same information. When people know what matters to you and the choices you would make for yourself, they can be sure to advocate for the choices that respect your wishes and preferences.

There are many ways to make a record of your wishes and preferences. Some examples might be to write a letter, make a video or record an audio note. Whatever you choose to do, you just need to make sure that people know your wishes and preferences.

Before you begin, tell us how you would like to record your wishes and preferences.

For example, I will use this page to make a summary and record something on my phone. I want people to hear my voice.

You can use the questions on the next page to make a summary of your wishes and preferences. Look back on the activities in the **My Values & Wishes** section and fill in the blanks.

My ACP Record

My Wishes and Preferences

- These are my favourite activities:

  _____

  _____

- I enjoy spending time with _____
- I like to start my day by _____
- I like to end my day by _____
- When things get hard I turn to _____
- These are the beliefs and traditions that are important to me:

  _____

  _____

These are my preferences for my health and personal care:

- I want to know _____ about how sick I am and what will happen.
- If I am unlikely to get better, I would want to know _____

You can print or save this page as your record of your wishes and preferences

My ACP Record

- Being in pain is _____ to me.
- My privacy is _____ to me.
- Being able to move around how I want is _____ to me.
- These things would make it more enjoyable if I could not move around how I want: _____
- Not being able to express myself, hear or share my thoughts would be _____ to me.
- If I could not express myself with words, I would want to:

  _____
- I would trust _____ to interpret my body language if I could not express myself in words.
- Asking for help is _____ to me.
- I would want support with _____
- I would want my care to include:

  _____

  _____

  _____

You can print or save this page as your record of your wishes and preferences

Congratulations, you have made a record of your wishes and preferences. Before we move on to looking at your support network and decision makers we would like to introduce you to Jane. We will check in with Jane throughout this guide and explore how using the guide helped her to make an ACP plan.

Jane's Journey

Jane made her plan a few months ago. This is her journey using this guide to learn about her wishes and preferences.

Jane learned about ACP after hearing about a friend's emergency hospital visit. Her friend Mo had a car accident and was not conscious when they arrived at the hospital. Their doctor needed to find someone quickly to make care decisions. Mo was not close to their mother but that is who was called. Mo made a full recovery but they were unhappy that someone who did not respect their life choices was the person making decisions about their healthcare. Mo shared with Jane how the experience had inspired them to make an Advance Care Plan.

Jane decided right away that she needed to make a plan too. She wanted to share what mattered to her with the people in her life. But, first she needed to figure out what she should share.

Jane found this guide on the ACP Canada website. She used it to help her think about her own wishes and preferences. The "What is Important to Me" activity helped Jane to learn that being outdoors and active gave her life meaning. Thinking about her wishes and preferences reminded Jane of her father's stroke and how the care choices her mother made led to him no longer being

able to enjoy the things he loved most in his life. Jane knew she didn't want to have a similar experience.

Jane knows it will not be an easy thing to share her wishes and preferences. To help herself feel ready Jane decides to write a letter. She writes about her father's story and how hard it was to see him unable to do what he loved at the end of his life. She shares how she would want to be cared for and what is most important to her. Jane's letter was the most personal way she could think of to share her wishes and preferences.

We will check in with Jane later to see how the rest of her planning journey goes.

3 My Support Network

In this section:

- Who is in My Support Network?
- Activity
  Naming My Support Network
- My ACP Record
  My Support Network Summary
- Choosing My Decision Maker
- Activity
  Choosing My Decision Maker
- Jane's Journey

Who is in My Support Network?

Your support network are the people who are there for you when you need help. This might include family, friends, and neighbours. It could also include spiritual leaders, healthcare or other professionals. A good question to ask yourself is, **who do you turn to for support during hard times?**

This section will help you find the important people in your life. To start we are going to help you identify all of the people in your support network. Then we will think about how these people can be a part of your advance care planning.

Your support network are the people in your life who give you help when you need it. They can also help you be your best version of you. They might help you reach personal and professional goals. They might also help when you are sick or need guidance.

Activity
Naming My Support Network

This activity will help you to name the people in your support network. Your support network is unique to you, some people might have a long list of people in their support network. Other people might only have one or two people. We are all unique and our support network is unique to us.

Take your time to think about these questions. Remember, there is no rush. You can do this alone or with the support of others.

- Think of the people and relationships in your life. Can you name the groups of people or types of relationships? Some examples could be family, friends, healthcare providers, or community supports.

For example, family, friends, my church, my healthcare team.

- Who are the people you look forward to seeing, talking to or being around? This could be family members, friends, or mentors. You might write down one name or many.

For example, my neighbour John, he is always smiling and my wife Anya.

- Who do you turn to for:

emotional comfort?	physical help?	friendship?
For example, my mom.	For example, my brother Jim.	For example, my best friend Sylvia.

- Are there people in your community who you feel connected to?

For example, I have known my pastor Joseph my whole life. My volunteer support worker is also someone I always like seeing.

- **Think about a time that your life was hard.**

Who was there to support you?

For example, my best friend Sally and my neighbour Jasper.

Was there anyone else who helped you but is not on your list so far?

For example, my uncle Joe, he gives me rides to the hospital all the time.

Can you share some of the ways that these people supported you?

For example, they brought me food and helped me get to appointments. They also kept me company.

- Do you think we should add anyone else?

For example, Aunt Betty, she is my favourite. She has always helped me.

Now you can use the ACP Record on the next page to make a list of all of the people you wrote down. This list is your personal support network. These are the people you can turn to for help.

My ACP Record

My Support Network Summary

Add the names of your support network people here:

_____

_____

_____

_____

_____

_____

_____

_____

You can print or save this page as your record of your wishes and preferences

Choosing My Decision Maker

Once you know who is in your support network it is time to choose a person (or people) to be your decision maker(s).

Your decision maker(s) might need to support you in expressing your wishes and preferences over a short or long period of time. There also could be a time when your decision maker(s) might need to act temporarily as your substitute decision maker(s) if you were ever unable to express your own wishes and preferences.

Choosing the right person (or people) to express your wishes and preferences if you aren't able to is an important part of the ACP process. This section will help you choose the right person or people to ask about being your decision maker(s).

If you do not name someone to be your substitute decision maker, your healthcare team will use a legal hierarchy. It goes a little like this:

1. your spouse or partner
2. an adult child
3. your parent
4. your sibling – brother, sister
5. any other relative

The hierarchy might be different where you live. Check in your local area to see what hierarchy they use.

The next activity is going to help you choose who you might want to ask to be your decision maker(s).

Some of the things you can think about as you answer the questions are:



- Who would you trust to make healthcare decisions that reflect your wishes and preferences?
- Who would be clear when they communicate with your health team?
- Who could make difficult decisions during stressful times?
- Who would be willing and available to give voice to your wishes and preferences if you were not able to do this yourself?

Before you begin the activity, let's look at Mo's story.

Mo is driving back to the city after a fun day trip when they get in a car accident. They suffer a lot of injuries and arrive at the hospital unconscious. Emergency doctors need to perform critical surgeries to help them. The surgeries might impact their quality of life. The doctors contact Mo's mother and she gives consent.

When Mo recovers they are upset to find out the choice for the surgery was made by their mother. They have not been in close contact with their mother for many years and Mo's mother does not know what is important to them.

Activity
Choosing My Decision Maker

- If you were in Mo's position, who would you want the doctor to call? **Write down the first 2-3 names that you think of.**

- Looking at the names you wrote down. Do you think they would make choices that you want? **Pick one of the options below.**

  ○ Yes ○ Maybe ○ No

- Is there anyone who you think would do a good job of making choices based on your wishes and everything that they know about you as a person and your preferences?

- What qualities do you want your decision maker to have?

For example, I would want them to be calm under pressure, strong but kind and thoughtful.

- Looking at the names you have written, who has these qualities?

- Would you add anyone else?

- In the past, who have you asked for advice? Or whose advice have you valued the most?

- Why did their advice help you?

For example, Bob, he is very smart. He made me think about things I had not thought about before.

- Would you want this person to share your health or personal care choices, even if they might affect how you live in the future?

For example, Elliott is really good at not always being stuck in how he thinks.

- Why could they be the right person (people)?

For example, he listens to what I want.

Now it is time to look back at your answers. Who have you written down? Ask yourself a few final questions.

- Based on your answers in the previous questions, who would you trust to express your wishes and preferences? Is there more than one person?

- Now think about the qualities of this person (these people) and how they deal with hard choices. Are these the qualities that you want in your decision maker(s)? **Pick one:**

  ○ Yes ○ Maybe ○ No

- Do you trust this person (these people) to express your choices if you were ever unable to express them yourself? **Pick one:**

  ○ Yes ○ Maybe ○ No

Amazing, you have taken a very important step in your advance care planning journey. You will need to ask each of these people if they agree to be your decision maker. Will you be asking them to be a supportive decision maker or a substitute decision maker or both? Make sure you are clear. If someone is not able to take on the role or is not comfortable being your decision maker you may need to find a different person or people.

You can use the next section to help you plan how you might ask people to be your decision maker(s) and how you will share your wishes and preferences with them.

Jane's Journey

After Jane thought about and recorded her wishes, and preferences she moved on to the "My Support Network" activity. Jane used this activity to help her find her support network and choose her decision makers.

Jane answered all the questions in the support network activity. She only had a small group of people who she was comfortable asking for help. Jane's support network was small but she felt very close to each of them. Jane knew that she could look for support from her family and her very close friends.

After thinking about the questions in the decision maker section Jane decided to ask her sister and her husband to be her decision makers. Jane loves her husband and they share all of their wishes and dreams with each other. But Jane knows he would find it hard to make choices for her healthcare. Jane's sister is her best friend and she trusts her to make the tough decisions. Together she feels that they will make the choices she wants. Jane also knows that if there ever comes a time she needs someone to support her in making her healthcare choices be heard both her husband and her sister would be there to help her.

4 Sharing My Wishes

In this section:

- Sharing My Wishes
- Activity
  Sharing My Wishes and Preferences
- My ACP Record
  My Decision Maker(s)
- Jane's Journey
- Sharing with My Healthcare and Social Support Team
- Activity
  Sharing with My Healthcare or Social Support Team

Sharing My Wishes

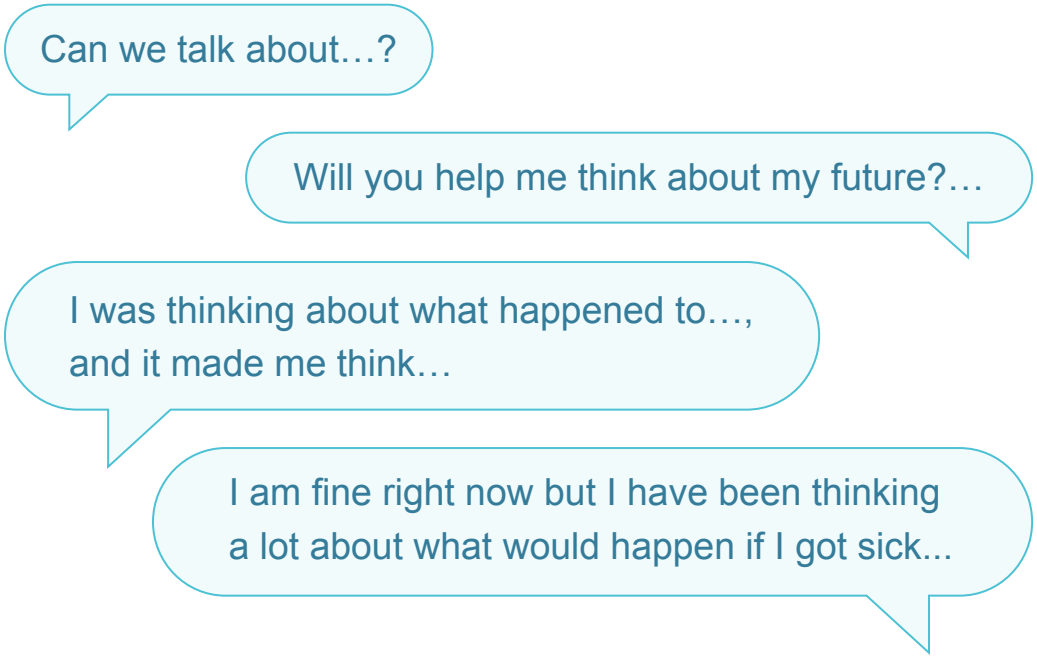
You have thought about and made a record of your wishes and preferences. You have also chosen who you will ask to be your decision maker(s). Now it is time to start sharing with your decision maker(s), your support network, and even your healthcare team. Sharing your wishes and preferences will help to make sure that everyone knows what you want and would choose for yourself. When everyone knows, they can support and honour your choices. You might think people know what matters most to you and what you would want. But they may not.

For some people sharing your wishes and preferences can be hard. It might bring up a lot of emotions. You might worry about what the other person will say or think. Being prepared is one way to help everyone to feel more at ease.

Here are some things you can do to get ready to share:

- **Find a quiet and comfortable place.**
  Make sure it works for both you and the other person or people.
- **Give yourself a lot of time.**
  You won't want to feel rushed and will need time to answer questions.
- **Bring this guide and your record of your wishes and preferences.**
  You will want to express your wishes and preferences. Your letter, video, or audio note can help to get things started.
- **Plan to meet more than once.**
  Everyone is going to process things in their own way. Make it clear that they can ask questions and it is ok if they do not feel the same as you. Then make plans to meet up again to keep sharing.

Even when you are ready to share, knowing how to begin can be hard. These are some of the ways that you could start:



from The Conversation Project

The next activity will help you plan when, where, and how to share your wishes and preferences. How you share might be different from one person to the next. You can have conversations with people one at a time or as a group. Sometimes sharing with a group helps to make sure everyone is hearing the same thing. You can also ask someone who supports you to help you with sharing.

You can use the questions in this activity to help you make your plan(s). Your answers might be different if you are planning to share with a group or a single person.

Activity
Sharing My Wishes and Preferences

- Who are you sharing with?

For example, my husband James and my sister Zahra.

- Will you have anyone come with you to support you?

For example, my social worker Zaina.

- Where would be a good place for you to meet?

For example, I will invite them to our local park. It is quiet, peaceful, and calm.

When would be a good time to meet?

For example, Saturday morning around 10am, so that we are not feeling rushed.

What will you bring with you?

For example, I will bring this guide, and my record of my wishes and preferences.

How will you get started?

For example, I will use my text to voice tablet and have it say, “I have been thinking about what matters to me and I wanted to share it with you.”

Now you have a plan for when and where you will share your wishes and preferences. You can use your **support network list** to help you make sure you are sharing with everyone who is important to you by checking off each person once you have shared with them.

You might find that some people are ready to listen and some are not. Some people might find these topics difficult. It is ok for people not to be ready. Give them time and let them know you would like to try again soon. Find a date and time that works for both of you.

Once someone has agreed to be your decision maker, you may need to have them appointed as your legal decision maker(s). There is more on this in the Next Steps section.

Once you have asked your decision maker(s) to be a part of your plan you should make a record of who they are. Be sure to store this with your record of your wishes and preferences. We will share more about storing your record in the next section.

My ACP Record

My Decision Maker(s)

Remember this is not a legal document and you will need to learn about what legal documents are required in your region to make sure your decision maker(s) is/are legally recognized.

Decision Maker 1

Name: _____

Contact Information: _____

_____

How I know them: _____

◯ Substitute Decision Maker ◯ Supportive Decision Maker

Decision Maker 2

Name: _____

Contact Information: _____

_____

How I know them: _____

◯ Substitute Decision Maker ◯ Supportive Decision Maker

You can print or save this page and keep it with your record of your wishes and preferences

Jane's Journey

Let's check in on Jane to see how things are going for her.

After Jane chooses her husband and sister to be her decision makers, she thinks it would be best to talk with both of them together.

Jane invited her sister and husband out for lunch to ask them to be her decision maker(s). At lunch Jane gave each of them a copy of her letter about her wishes and preferences. Once they had read her letter she shared more about what she wanted to happen if she became ill and the kind of support she hoped they could give her. Jane's sister felt very similar to Jane and agreed to be her decision maker.

Jane's husband shared that he would find it really hard to make difficult choices but that he understood her preferences and why she felt the way she did. He agreed to support what she wants and felt that being able to lean on Jane's sister would help.

Jane plans to set aside one day a year to rewrite her letter and then read it with her husband and sister. She will take this time to think about her plan and see if anything needs to change.

Sharing with My Healthcare and Social Support Team

You may also want to share your wishes and preferences with your healthcare or social support team. You might want to express to them what is most important to you or what you are not willing to risk when it comes to your health. You could share what matters most to you for your future and how you would feel if your care affected your quality of life. Working with your healthcare team will help you to get the care and treatment that match your wishes and preferences.



When we talk about your “Quality of Life” we are talking about your health, wellness, and comfort. Enjoyment of day-to-day life, comfort, and health may have a very different meaning depending on your culture, abilities, and other factors. You will have your own individual definition of what “Quality of Life” means for you.

Here are some things you can do when you are sharing with someone on your healthcare or social support team:

- **Make a list of the things you want to express.**
  Show this to your provider at the beginning of your appointment. You could say “Hi, here are some things I have been wanting to share so I made a list. I want to talk about this today.”, or express your desire to explore your list.
- **Be open and honest.**
  If you want to express your wishes and preferences, let your provider know. You could bring this guide and share what you have written and how you feel.
- **Ask questions.**
  It is ok to ask questions if something does not make sense. Don’t be afraid to say “Could you say that again, but in plain language?”. You can also ask them to repeat back what you shared to make sure they understood. You could ask “Did you understand what I was sharing?”.
- **Be a partner.**
  Let your healthcare team or social support team know that you want to work with them. Ask questions. Ask for their opinions. Ask for their help. Share what matters most to you. Let them know that these are your wishes. You can also tell them that your wishes and preferences might change. Let them know that you want to be part of the conversation and know your options.

When you are ready to share with your healthcare team or social support team, you can use this activity to get ready. You can also take this guide with you to have somewhere to record your questions and answers.

Activity
Sharing with My Healthcare Team or Social Support Team

- What part of your wishes and preferences do you want to share with your healthcare and social support team?

For example, my privacy is very important. Being able to move around is really important to me. My decision makers are my friend, John and my wife, Susan.

- Do you have any questions for your healthcare or social support team? Maybe you want to know more about your diagnosis, treatment options and what you can expect. Maybe you want to know how they feel about your preferences.

For example, what will happen if my illness gets worse? Will my treatment make it harder for me to move easily?

Would you be comfortable with me choosing not to have a treatment that would affect how I live my day-to-day life?

- How will you start your conversation with your healthcare or social support team?

For example, I will share that I have been making my advance care plan and I want them to know about my wishes and preferences.

This space is for you to use to make notes about what you shared and the answers you were given:

5 Storing My Record

In this section:

My ACP Record
Storing My Record

Jane's Journey

My ACP Record

Storing My Record

Now it is time to put your plan and all of your other legal documents in one place. You will need to find a safe and easy to access spot. Sometimes people will keep things in a digital folder. Other people will keep them as paper documents together in one folder.

This activity will help you choose how you want to store your record. Then be sure it is in a safe place that your decision maker(s) can find and access easily.

My ACP Record

- How do you prefer to keep important documents? **Pick one:**

  ○ Paper ○ Digital

- Where will you store your ACP Record?

  _____

- Will people need to know a password? **Pick one:**

  ○ Yes ○ No

- Will people need a key to access your record? **Pick one:**

  ○ Yes ○ No

If you answered yes to either of the two previous questions, make sure your decision maker(s) have the password. If your record is locked away somewhere make sure they know where the key is.

- Will you store other documents with your ACP Record? Use this space to make a list of all the documents you will store together.

  ○ My will

  ○ My legal documents

  ○ My support network contact list

  _____

  _____

You might want to keep your ACP Record with your will or financial plan. That way everything will be in one place when you are ready to make any updates.

- Have you told your decision maker(s) where to find your ACP Record?

  ○ Yes ○ No

You can print or save this page and keep it with your other record pages

Jane's Journey

Let's do one final check in with Jane to see where she stores her ACP plan.

After sharing her wishes and preferences with her family and friends Jane finishes up using this guide and makes a plan for how she is going to store her important documents.

Jane recorded her wishes and preferences by writing a letter. Then she shared the letter with her decision makers. Jane explored the legal requirements where she lives and downloaded the forms she needed to make sure that her decision makers were legally appointed.

Once she had the forms completed she printed everything and put them in a folder in her home filing cabinet. The filing cabinet is locked and she made sure that both her husband and sister knew where the key was and where to find the files.

Jane also made a note on the contacts for her husband and sister in her phone that said "Decision Maker" just in case someone looked in her phone in an emergency.

6 My Next Steps

In this section:

- Reviewing My Plan
- Looking at the Legal Side
- Thank You

Congratulations on completing your guide. You did it!

Let's review all the things you have done. You can use this list to make sure you have done everything.

- ◯ You thought about your values and wishes.
- ◯ You thought about what is important for your care and your preferences.
- ◯ You made a record of your wishes and preferences.
- ◯ You named the people in your support network.
- ◯ You have chosen a decision maker(s).
- ◯ You shared your wishes, values, and choices with your decision maker(s).
- ◯ You shared your wishes, values, and choices with your support network.
- ◯ You shared your wishes, values, and choices with your healthcare team.
- ◯ You made a record for your decision maker(s).
- ◯ You put your record together and with other important documents in a safe and easy to find place.

You have taken an important step for you and your loved ones. Recording your wishes and preferences and sharing with the people who matter to you will ensure that your voice is heard.

Let's look at some of the next steps you can take to continue your advance care planning journey.

Reviewing My Plan

Keeping your plan up to date is important. You want to be sure that your wishes and preferences match what's happening in your life.

It is important to remind yourself to come back and check what is in your plan. Answer these questions to make sure you don’t forget!

- How often will you review your plan?

For example, I will make a promise to look at this every year on the day after my birthday.

- Will you ask anyone to be part of your review?

For example, I will ask my brother to check in with me.

- How will you set a reminder?

For example, I will put a reminder in my digital calendar with an alarm.

Looking at the Legal Side

Once you have a plan and have chosen your decision maker(s), you will need to understand what you need to do to have them legally appointed. This is important to make sure your wishes and preferences are supported and respected.

Based on where you live and your choices, the legal process will look different. Remember, this guide is not a legal document. Each province and territory has its own laws and words they use to describe a decision maker. Depending on where you live you might need to appoint a **Substitute Decision Maker (SDM)**, **Representative**, **Power of Attorney for Personal Care (POA)** or **Decision Making Supporter**. All these terms mean that you need to identify someone who can share your preferences and advocate for care that you would want if you are not able to express yourself or need support in doing so.

You may decide to seek legal advice to explore requirements. Legal representatives can help to make sure you have the right legal documents. Or, you may find free or inexpensive forms online.

You can find a link to local resources on the ACP website: www.advancecareplanning.ca

Thank You

Thank you for going on this journey with us.

If you enjoyed using this guide to make your advance care plan or found any of it difficult to use, please let us know. We want to hear from you and learn how we can do better to meet your advance care planning needs.

Contact us by messaging us at info@advancecareplanning.ca.

Personal Directives and Decision Makers in Nova Scotia: What You Need to Know

Now that you've taken time to **Think, Learn, Choose, Share, and Record** your wishes, here's what you need to know about Personal Directives and decision makers in Nova Scotia.

What is a Personal Directive?

A Personal Directive is a legal, written document where you:

- Describe your wishes for **personal and health care**.
- Name someone you trust to make decisions for you if you cannot do so yourself.

You **do not need a lawyer** to complete a Personal Directive, but some people choose to consult one to ensure everything is done correctly.

The person you name is called your **Named Delegate (or Delegate)**.

Tips for completing your Personal Directive:

- Use your ACP reflections and conversations to clearly express your wishes.
- Include instructions that your Delegate can follow if circumstances change.

What is a Named Delegate?

Your **Named Delegate** is the person you choose to make decisions on your behalf.

They may make decisions about:

- Health care and treatments
- Nutrition, hygiene, and comfort
- Where you live or receive care (e.g., home, nursing facility)
- Recreation and support services

How Delegates make decisions:

1. Follow the instructions in your Personal Directive.
2. Consider changes in your wishes or circumstances.
3. If no instructions exist:
    a. Decide based on what they believe you would want.
    b. If unsure, decide based on your best interest.

You can:

- Name one main Delegate.
- Assign different Delegates for different decisions.
- Name an alternate Delegate if the main Delegate is unavailable.

Delegate requirements:

- 19 years of age or older
- Know you well
- Willing to act on your behalf
- Reachable when needed

What is a Statutory Decision Maker?

If you do not name a Delegate, Nova Scotia law assigns a **Statutory Decision Maker.**

Hierarchy:

1. Spouse or partner
2. Adult child
3. Parent
4. Sibling

- If no one qualifies, the **Public Trustee** may make decisions.

They may make decisions about:

- Health care
- Home care
- Placement (e.g., long-term care)

Decision rules:

- Follow your known wishes and values.
- If unknown, act in your **best interest**.
- Must have had contact with you within the past year.

Personal Directive and ACP Tips

- Keep your Personal Directive with your other ACP materials so your wishes are easy to find and follow.
- Many people keep it in a visible, accessible place, like on the refrigerator.

Related Terms and References

Advance Care Planning (ACP): This means thinking about what matters to you, sharing with others, and recording your wishes in case you are unable to express your wishes yourself.

Personal Directive: This is a legal document stating your wishes for personal and health care, and naming someone to make decisions if you cannot. https://novascotia.ca/just/pda/ https://www.legalinfo.org/personaldirective

Named Delegate (Delegate): This is the person you choose to make decisions on your behalf, following your wishes.

Alternate Delegate: This is a backup person in case your main Delegate is unavailable.

Statutory Decision Maker: This is the person the law assigns to make decisions if you have not named a Delegate.

Substitute Decision Maker (SDM): This is the term for anyone legally allowed to make decisions for you when you cannot. It includes Delegates, Statutory Decision Makers, guardians, or a Public Trustee.

Public Trustee: This is a government official who may make decisions if there is no family or Delegate is available.

Will: A will is a legal document that explains how your property, money, and belongings are distributed after you die. It can also can name guardians for your children. A will does not cover health or personal care like ACP and a Personal Directive does. https://www.legalinfo.org/i-have-a-legal-question/wills-estates-law/

Executor: This is the person you name in your will to carry out your wishes, pay debts, and distribute your property.

Medical Assistance in Dying (MAiD): MAiD is a legal healthcare option in Nova Scotia that allows a doctor or nurse practitioner to help a person die at their voluntary and informed request. To be eligible, a person must be 18 or older, capable of making their own healthcare decisions, have a serious and incurable medical condition, and know about other care options, including palliative care. https://www.nshealth.ca/maid

Expected Death at Home: An “expected death at home” is when a person with a serious, life-limiting illness is known to be nearing the end of life and is expected to die at home. Plans and medical documents are completed in advance so the person can stay at home comfortably. When everything is properly in place, emergency services do not need to be called, and a healthcare provider follows the appropriate provincial process to support and manage the death. To learn more, visit https://www.nshealth.ca/patient-education-resources/2565

Learn More

For more information about Advance Care Planning in Nova Scotia, contact:

Nova Scotia Hospice Palliative Care Association (NSHPCA)

Website: www.nshpca.ca
Email: info@nshpca.ca
Phone: 782-321-9181

About NSHPCA

NSHPCA is a provincial, non-profit organization providing leadership, education, and advocacy in hospice palliative care, grief, and emotional wellness.

Mission: Lead and advocate for quality palliative care and grief support by fostering education, collaboration, research, and innovation.

Vision: All people in Nova Scotia can access compassionate, culturally responsive palliative care and grief support when and where they need it.

Values:

- Equity and inclusion
- Community voice and partnership
- Accountability and transparency
- Evidence and learning
- Humility and respect
- Agility and Responsibility

NOVA SCOTIA

Personal Directive

I, _____, make this Personal Directive.
Name of Maker

This Personal Directive is made pursuant to the Personal Directives Act and takes effect if I am not capable of making a decision regarding my personal care.

I have placed my initials and my witness has placed his/her initials next to the sections in this document that I want to be part of my Personal Directive.

1. Consultation when assessing capacity (optional)

_____ _____
Witness' Initials Your Initials

The person making the assessment of my capacity is to consult with the following person when making the assessment.

Name: _____
Print Name, Title or Position of Individual

Address: _____
Street Address

_____
City/Town Province

Phone: _____ Email: _____
Home Business

2. Revoking (Cancelling) Other Directions (optional)

_____ _____
Witness' Initials Your Initials

I revoke (cancel) all previous instructions, personal directives, and authorizations, including those made pursuant to the Medical Consent Act.

OR

_____ _____
Witness' Initials Your Initials

I revoke (cancel) only the following instructions, personal directives or authorizations:

Date: _____

Description:

_____

_____

3. Authorization to Act as Delegate (optional)

Witness' Initials _____ Your Initials _____

I authorize the following person to act as my delegate to make personal care decisions on my behalf for all personal matters, of a non-financial nature, that relate to me.

Name: _____
Print Name of Delegate

Address: _____
Street Address

_____
City/Town Province

Phone: _____ Email: _____
Home Business

If my delegate is unable, unwilling or unavailable to make a personal care decision, I authorize the following person to act as my alternate delegate.

Name: _____
Print Name of Alternate Delegate

Address: _____
Street Address

_____
City/Town Province

Phone: _____ Email: _____
Home Business

OR

Witness' Initials _____ Your Initials _____

I want to authorize more than one delegate to make different personal care decisions on my behalf. I authorize the following individuals to act as my delegates and alternate delegates (if the delegate is unable, unwilling or unavailable to make a personal care decision) to make personal care decisions on my behalf for all the following personal care matters, of a non-financial nature, that relate to me:

health care	_____ Name of Delegate and contact information	_____ Name of Alternate Delegate and contact information
home care services	_____ Name of Delegate and contact information	_____ Name of Alternate Delegate and contact information

accommodation, including placement in a continuing-care home	Name of Delegate and contact information	Name of Alternate Delegate and contact information
with whom I may live and associate	Name of Delegate and contact information	Name of Alternate Delegate and contact information
participation in social activities	Name of Delegate and contact information	Name of Alternate Delegate and contact information
participation in educational activities	Name of Delegate and contact information	Name of Alternate Delegate and contact information
participation in employment activities	Name of Delegate and contact information	Name of Alternate Delegate and contact information
other personal care matters as follows:	Name of Delegate and contact information	Name of Alternate Delegate and contact information

4. No Delegate Authorized (optional)

_____ _____
Witness' Initials Your Initials

I **DO NOT** wish to authorize a delegate, but have provided instructions in section 5 for persons who intend to provide personal care services to me.

5. Specific Instructions (optional)

I instruct my delegate(s) to carry out the following specific instructions when making decisions about my personal care:

additional page attached? ❑ Yes ❑ No

Witness' Initials _____ Your Initials _____

If I have not designated a delegate(s), or if my delegate(s) and alternate delegate(s) are unable, unwilling or unavailable to make a personal care decision, I instruct all persons who intend to provide personal care services to me to follow the following instructions that are relevant to the decisions to be made:

_____

_____

_____

_____

additional page attached? ❑ Yes ❑ No

6. Other Information (optional)

Witness' Initials _____ Your Initials _____

I provide the following information to help my delegate(s) or statutory decision-maker understand my values, beliefs and wishes when making decisions about my personal care:

_____

_____

_____

_____

additional page attached? ❑ Yes ❑ No

7. Instructions about Statutory Decision-makers (optional)

Witness' Initials _____ Your Initials _____

I **DO NOT** wish to authorize a delegate and am comfortable with a relative authorized under section 14 of the Personal Directives Act making decisions on my behalf about health care, home care and placement in a continuing care home, except I **DO NOT** want the following relative(s) making decisions on my behalf:

_____

Name Relationship

8. Consultation when Delegate Making Decisions (optional)

_____ _____
Witness' Initials Your Initials

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

Name: _____
Print Name of Delegate

Address: _____
Street Address

_____
City/Town Province

Phone: _____ Email: _____
Home Business

9. Notification (optional)

_____ _____
Witness' Initials Your Initials

If it is determined that I lack capacity to make a personal care decision, I instruct the person making the determination to notify me, the delegate(s) I have authorized in this Personal Directive, if any, and the following people:

_____

_____

_____

_____ _____
Witness' Initials Your Initials

If is determined that I lack capacity to make a personal care decision, the following people are not to be notified of the determination:

_____

_____

_____

10. Compensation for Personal Care Services (optional)

_____ _____
Witness' Initials Your Initials

My delegate, _____, is authorized to
Name of Delegate
receive compensation for providing me with personal care services on the following terms:

_____

_____

_____

11. Remuneration for Delegate (optional)

Witness' Initials _____ Your Initials _____

My delegate, _____, is authorized
Name of Delegate
to receive remuneration for exercising his/her authority under this personal directive on the following terms:

_____

_____

_____

12. Signatures (mandatory)

Signed by me in the presence of my witness at _____, in the Province of
Location
Nova Scotia, this _____ day of _____, _____.
Day Month Year

_____
Printed Name of Witness

_____
Printed Name of Maker

_____
Relationship to Maker

_____
Signature of Maker in the presence of the Witness

_____
Signature of Witness in the presence of the Maker

_____
Street Address

_____
Street Address

_____
City/Town

_____
City/Town

_____
Province

_____
Province

_____
Home Phone Number Business Phone Number

_____
Home Phone Number Business Phone Number

_____
Email

_____
Email

OR (where Maker physically unable to sign)

Signed on behalf of the Maker, _____, in the presence of the
Name of Maker

Maker **and** in the presence of the witness at _____, in the Province of
Location

Nova Scotia, this _____ day of _____, _____.
Day Month Year

_____	_____
Print Name of Person signing on behalf of Maker	Print Name of Witness
	_____
	Relationship to Maker
_____	_____
Signature of Person signing on behalf of Maker in the presence of the Maker	Signature of Witness in the presence of the Maker
_____	_____
Street Address	Street Address
_____	_____
City/Town	City/Town
_____	_____
Province	Province
_____	_____
Home Phone Number Business Phone Number	Home Phone Number Business Phone Number
_____	_____
Email	Email

Notes

Advance Care Planning Canada

For more information about Advance Care Planning Canada, please visit our website at: www.advancecareplanning.ca

NSHPCA
Nova Scotia Hospice Palliative Care Association

For more information about Nova Scotia Hopsice Palliative Care Association, please visit our website at: nshpca.ca

E-mail: info@nshpca.ca **Telephone:** 782-321-9181