TrueNTH is a revolutionary new program that helps men living with prostate cancer to get access to quality of life-enhancing information, care and support including treatment information, lifestyle management, experiences shared with other prostate cancer survivors, and better access to healthcare professionals.

This work was awarded by Prostate Cancer Canada and is proudly funded by the Movember Foundation. This workbook has been adapted from the “Speak Up” advance care planning campaign.

We also wish to recognize and thank our Advisory Committee for generously giving their time in reviewing this document.

FOR MORE INFORMATION about advance care planning, or to start advance care planning online, please visit our website at: acp.trueth.ca

Or contact us by e-mail at acp@truenth.ca

The information provided within this workbook is included as a public service and for general reference only. Every effort is made to ensure the accuracy of the information found here. However, this information is not considered legal, medical or financial advice and does not replace the specific medical, legal or financial advice that you might receive or the need for such advice. If you have questions about your health or about medical issues, speak with a health care professional. If you have questions about your or someone else’s legal rights, speak with a lawyer or contact a community legal clinic.
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Introduction

What is “Advance Care Planning”?

If your health deteriorated to the point where you couldn't speak for yourself, who would speak for you and make decisions about your care? Would they know what to do?

Advance Care Planning is about:

• Reflecting on your values, wishes and preferences for future care;
• Deciding on your Substitute Decision Maker(s);
• Having conversations with your Substitute Decision Maker(s), family and friends to let them know your future health and personal care wishes in case you are unable to speak for yourself; and
• Giving your loved ones peace of mind in making decisions about your care and treatment during a difficult time.

Important Points to Remember about Advance Care Planning:

• You must decide who will be your Substitute Decision Maker - someone who will speak on your behalf and make decisions for you when you are not able to do so yourself. You can have more than one substitute decision maker;
• You can change your mind at any time. Your substitute decision maker(s) will only be asked to make decisions if you are not capable of speaking for yourself; and
• Your family and other caregivers will appreciate knowing your wishes if they are called upon to make decisions on your behalf.

The Facts

• Only about half of Canadians have had a discussion with a family member or friend about what they would want or not want if they were ill and unable to communicate.
• That means 50% of families don’t know their loved one's wishes – and may have some very difficult decisions to make.
• About six in ten Canadians believe that it’s extremely important to talk to someone about their end-of-life care preferences – but only 45% have done so.
• Six in ten Canadians either personally suffer from a chronic illness (such as prostate cancer) or have a sufferer in their immediate family.
• Canadians are most likely to have these conversations with family members – this is the case among one-third of Canadians who have had a conversation.
• Canadians feel that being afraid of death is the strongest reason to avoid having the discussion. They say that these conversations ‘creep them out’.
• In addition, Canadians avoid discussing end-of-life care because they do not want to upset their family members or they believe there's no reason to think about it when they are healthy.

Notes:

Why is Advance Care Planning important?

Healthcare decision-making can be very complex. However, men diagnosed with prostate cancer may find it easier to make decisions when they have thought about and shared their values and beliefs ahead of time.

Advance care planning can ease the burden on your loved ones by helping them understand your wishes so they can confidently speak on your behalf, should you be unable to do so.

Advance care planning is important for everyone as life can take many twists and turns. Imagine:

One day, without any warning, you find yourself in a hospital with a life-threatening illness. You are unable to speak for yourself – you do not recognize your family or friends. Your doctors do not feel that you will leave the hospital alive. Do you want to be kept alive using machines? Does anyone know your wishes? Who will make decisions for you?

You are well now. Your treatment has been successful, and your doctor believes you will live many, healthy years. However, you are concerned that at some time in the future your illness may recur, or you may develop a new, life-limiting illness. How will you make your wishes known? Who will make decisions for you?

You are at the beginning stages of Alzheimer’s, and you know that at some point you will not be able to recognize people or make your own decisions. How will you make your wishes known? Who will make decisions for you?
What is advance care planning?
Advance care planning is the process of reflecting on and sharing your values, wishes and preferences for future care. It involves deciding on your Substitute Decision Maker(s) – the person(s) who will make decisions on your behalf if you are incapable of doing so. Advance care planning is a way to make sure there is someone who knows your wishes and can give or refuse consent for you. It’s a way to give your family and friends the confidence to make health care decisions that reflect what’s important to you.

Is it only men with prostate cancer who need to do advance care planning?
Not at all. Everyone should do advance care planning. You never know when you may face an unexpected event or illness and will be unable to make your wishes known. You may hope that you will be able to communicate until the very end but most deaths do not occur this way.

When does my substitute decision maker have to make decisions?
Healthcare providers only turn to your substitute decision maker(s) if you are unable to make your own health care decisions (for example, you are in a coma or your illness has impaired your ability to make decisions). If you have recorded your wishes in some way, your substitute decision maker(s) can use this to guide your care and advocate for your wishes.

What if I change my mind?
Our lives – and the people around us – change over time. You will want to review your wishes regularly to be sure it still reflects your values/preferences and that you are comfortable with your Substitute Decision Maker. Remember, your substitute decision maker will only be asked if you cannot speak for yourself.

What if my Substitute Decision Maker is not able or willing to make decisions for me?
Health care professionals will approach family members as directed in provincial or territorial legislations. Visit our website (acp.truenth.ca) to learn more about the laws surrounding substitute decision makers in your province/territory.

I have a Living Will – isn’t that good enough?
In Canada there is no such legal document called a “living will”. In some provinces/territories you can create a legal document called an Advance or Personal Directive – where you express your wishes. In others, you cannot. Check acp.truenth.ca for the laws in your province/territory. It is important that you have a conversation with those who will make decisions about your care – they may have questions about your wishes. You should also review your wishes regularly to be sure that they still reflect your feelings, beliefs and values about end-of-life care.

My family will know what to do - why do I have to write it down?
Writing down your wishes helps to ensure your wishes are clear for everyone. You may believe that they know what to do – but perhaps they don’t. For example, you may have said something like ‘pull the plug if I’m a vegetable’ – but you need to be clear about what that really means to you. Your family may also have questions about the choices that you’ve made. Our website (acp.truenth.ca) contains links to relevant provincial/territorial resources.
How to use this Workbook

This workbook will help you step by step to reflect on and to record your future health care wishes. It is all about your wishes so take as much time as you need.

You can move back and forth between the chapters, skip questions and get back to them at a later point, and you can add your own wishes and thoughts.

You are ready whenever you feel you have included everything you want your substitute decision maker and your loved ones to know. You can make changes at any point.

How do I do advance care planning?

1. THINK about your values – what is important to you – and your wishes regarding future healthcare choices.

2. LEARN about medical information that is relevant to your health concerns (prognosis, benefits, risks, possible outcomes, end-of-life care).

3. DECIDE who will be your substitute decision maker. Someone who would honour and follow your wishes, and will make medical decisions on your behalf should you become incapable of doing so.

4. TALK with your substitute decision maker, your loved ones, and health care providers.

5. RECORD your values and wishes and your substitute decision maker(s).
Let’s get started: Step 1

Step 1: THINK

Think about what’s right for you.

This section of the workbook will help you think about what’s important to you – and what you’d want people to know if you couldn’t speak for yourself. Begin by reflecting on your values, beliefs and understanding about your prostate cancer, your treatments as well as end-of-life care or specific medical interventions.

Think about any situations that you may have experienced with others and how it made you feel. You should also speak with your healthcare providers to ensure you have accurate information to make decisions about medical procedures.

Start by asking yourself the following questions about your values and beliefs, and what you would like others to know:

What’s important to me?

1. __________________________  2. __________________________  3. __________________________

What makes my life meaningful?
(For example, spending time with family and friends, being able to practice my faith, being active, my work, being able to do my hobbies, my pet)

What brings me happiness each day?
Write down three things that make you happy and make a day good for you (e.g. drinking a cold beer, enjoying a good meal, playing with the grandchildren, walking in the sun, talking to your partner)

1. __________________________________________
2. __________________________________________
3. __________________________________________

Questions to ask yourself about your health:

What do I value most in terms of my mental and physical health?
Choose any of these that are important to you – and add other comments if you wish.

- Being able to live independently
- Be able to recognize others
- Being able to communicate with others
- Having my privacy
- Being able to still do my hobbies
- Keeping my dignity
- Having family and friends nearby
- Other __________________________
What do I want others to know about my prostate cancer?

How do my decisions about my prostate cancer, my care and my treatment affect my loved ones? Does this change the way I feel about treatment?

Do I have fears or worries regarding my prostate cancer treatment? If so, who can I talk to?

If my prostate cancer gets worse, where would I prefer to get my care?
(For example, at home, in a health care institution)

What would make prolonging my life UNACCEPTABLE for me?
Choose any of these that are unacceptable to you – and add other comments if you wish.
- Being in a coma most of the time
- Loss of dignity
- Not being able to communicate with others
- Being a burden to family members
- A loss of privacy
- Losing control of my bodily functions
- Being in pain
- Having to stay in bed but still able to communicate with others
- Being kept alive with machines with no chance of survival
- Other

Questions to ask yourself about end of life:
When I think about dying, I worry about certain things happening:
Choose any of these that are unacceptable to you – and add other comments if you wish.
- Being in pain
- Struggling to breathe
- Being alone
- Losing my dignity
- Other
If I were nearing death, what would I want to make things more peaceful for me?  
Choose any of these that are important to you – and add other comments if you wish.

☐ Family and friends nearby  
☐ Privacy  
☐ Be able to die at home  
☐ Have spiritual support  
☐ Having specific music played  
☐ Having specific photos  
☐ Other ________________________________

Do my religious, cultural or personal beliefs affect my decisions? In what ways?

Palliative care is health care for individuals and families who are living with a life-limiting illness. Palliative care starts at the time of diagnosis and includes end-of-life care. If possible, would I prefer to receive palliative care at home, in a hospice or in the hospital? (To learn about the differences between these three settings, see below.)

Where would I like to die?

☐ Home  
☐ Hospital  
☐ Hospice (institution where palliative care is provided in a home-like setting)

What might change my mind about my choice? Have I made arrangements?

Here are the differences between each of these three settings:

1. HOME - Palliative and end-of-life care is often provided in people's homes through home care programs. These programs offer professional nursing care and a variety of home support services. There may be other services available in some communities to help people to remain at home. These include:
   • volunteer services
   • day programs offered for the ill family member in a variety of places in the community
   • pain and symptom management teams
   • 24-hour response teams

2. HOSPITALS - Some hospitals have special palliative and end-of-life care units. Others set aside a certain number of beds in different units of the hospital for people needing palliative care. Hospitals may also have a palliative care team made up of health professionals who are specialists in palliative care.

3. HOSPICES - In Canada, there are only a few residential hospices—separate buildings or apartments where palliative end-of-life care is provided in a home-like setting. Some people move into hospices to receive care on a 24-hour basis.
Is there anything that feels “undone” about my life?

Questions relating to after death:

Do I want my organs and tissue to be donated?

☐ Yes
☐ No
☐ I don’t know

If you do wish to donate your organ(s) and tissue, have you made the appropriate arrangements?

☐ Yes
☐ No (Consider visiting the website healthycanadians.gc.ca and click on “Diseases and conditions” to learn more about the organ and tissue donation process).

Other wishes and thoughts (write down anything that would help others understand and support you at the end of life)
Step 2: LEARN

Learn about end-of-life care options and procedures.

By learning more about medical terms and treatments, and legal requirements, you can make better decisions about your plan.

You might have a number of questions during your prostate cancer care and treatment. It’s important to discuss them with your doctor and other care providers so that you can make informed decisions about your advance care plan.

Learning about your prostate cancer and what to expect can help you decide what is most important to you. Talk to your doctor to gather information about:

- Current status of your prostate cancer
- Prognosis – or what you will experience in the future
- Possible medical treatments/what to expect from them

Make sure that you ask questions throughout your prostate cancer treatment, not just at the beginning. It’s important to tell your health care team how much information you want, and what is important to you.

Questions to ask your doctor about your prostate cancer and treatment plans:

- “Tell me what I can expect from my prostate cancer? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?”
- “Is the treatment meant to cure the prostate cancer or just make me more comfortable? Or both?”
- “What options are available if I don’t want to start or continue treatment?”
- “What side effects or complications could be caused by the treatment?”
- “How would I know if the prostate cancer has progressed? Will there be any signs or symptoms?”
- “What are my options if my health quickly gets worse?”
- “When would someone consider palliative care? What palliative care services are available in my community?”
- “What about life prolonging or life sustaining treatments? How do I decide whether or not to have these treatments?”

Questions to ask yourself about medical intervention:

How important is it that I be comfortable and suffer as little as possible?
- [ ] Not at all important
- [ ] Not too important
- [ ] Somewhat important
- [ ] Very important

How important is it that I live as long as possible?
- [ ] Not at all important
- [ ] Not too important
- [ ] Somewhat important
- [ ] Very important
How important is it that I avoid being attached to machines and tubes?

- [ ] Not at all important
- [ ] Not too important
- [ ] Somewhat important
- [ ] Very important

How important is it that I respect the wishes of family members regarding my care?

- [ ] Not at all important
- [ ] Not too important
- [ ] Somewhat important
- [ ] Very important

How important is it that I am involved in making decisions about my care?

- [ ] Not at all important
- [ ] Not too important
- [ ] Somewhat important
- [ ] Very important

Please turn to the Appendix on page 19 of this workbook for explanations of common medical and legal terms used in advance care planning.
Step 3: DECIDE

Decide who will make medical decisions on your behalf should you become incapable of doing so.

You should decide who will make medical decisions and speak for you if you become too sick and cannot speak for yourself.

Think carefully about who you feel would honour and follow your wishes and would be willing and able to make these decisions for you. This person will be your Substitute Decision Maker(s).

You can have more than one substitute decision maker. They may be your husband or wife, or an adult child, or even a good friend.

Common Questions on Substitute Decision Makers:

What does a substitute decision maker do?

Your Substitute Decision Maker:

- Will give or refuse consent to treatments proposed by a health practitioner if you are incapable of doing so yourself.
- Will make medical decisions on your behalf when you are incapable of communicating your wishes because of illness or injury.

How do I choose a Substitute Decision Maker(s)?

When choosing a Substitute Decision Maker you should ask yourself:

- Do I trust this person to make healthcare decisions with my healthcare team based on my values and wishes?
- Are they able to communicate clearly?
- Can they make difficult decisions during stressful times?
- Is this person willing and available to speak for me if I couldn’t speak for myself?

What if there is no one to be my substitute decision maker?

In all provinces/territories the law will provide for someone to make decisions on your behalf. Check out the laws and guidelines in your province/territory by visiting our website: acp.truenth.ca

What if I change my mind?

It’s ok to change who your substitute decision maker is! Life changes, and so may your wishes for end-of-life care. It’s important to regularly review your wishes and your choice of Substitute Decision Maker, especially if your health changes, or there’s a major change in your life.

On the next page, you will be asked to provide information about your Substitute Decision Maker.
My Substitute Decision Maker(s)
I have discussed my wishes for future healthcare with the person named below.

**My Substitute Decision Maker is:**

Full Name: ____________________________________________________________

Relationship: __________________________________________________________

Telephone ___________________________ Cell phone: __________________________

Address: __________________________________________________________________

________________________________________________________________________

E-mail: ________________________________________________________________

**I have also discussed my wishes with the following people:**

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship to me</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

**Note:** some provinces and territories require you to complete certain legal forms to identify your Substitute Decision Maker. Find out more by visiting our website [acp.truenth.ca](http://acp.truenth.ca)
Step 4: TALK

Begin the Conversation

It's time to talk to your Substitute Decision Maker, your family and your health team. These conversations may not be easy – but they will help you and your loved ones know what's important to you.

Your Substitute Decision Maker(s) may find the conversation difficult, or may be relieved to know exactly what kind of care you would like to receive. Make sure that your Substitute Decision Maker(s) have a copy of your wishes.

Advance care planning conversations may reveal that you and your loved ones disagree. That's okay. It's important to simply know this, and to continue talking about it now—not during a medical crisis.

Break the ice

Register to the TrueNTH Advance Care Planning Portal on our website (acp.trueth.ca) and check out the health library. There you will be able to print an e-card to help start the conversation with your substitute decision maker/loved ones.

Here are some tips on how you can start the conversation:

Be straightforward

• “I have just filled out that workbook and I want to share it with you.”

• “My prostate cancer prognosis is good but in case decisions need to be made on my behalf I want you to know what I would want.”

• “To make your life easier when the time comes let’s talk about my wishes for my future health care.”

Find an example from your family

• “Does anyone know how Jason’s sister died? No one ever talked about it. I wonder if she died at home or in a hospital?”

• “Do you remember my friend Frank who was in a coma for a while? I wonder if there was any argument about keeping him on that ventilator?”

Blame someone else for the necessity of the conversation

• “Pastor Jones raised the question about what choices we would make at the ends of our lives, and I realized I don’t know what your choices would be.... any thoughts?”

• “My urologist wants me to think about my future care and to do advance care planning. Will you help me?”

Find an example from the news

• “How sad for the parents of the child who died last week in the car accident. But how generous they were to donate his organs.”

• “Remember the man who was in a coma for years? I would never want that to happen to me.”

Recommend a book, a movie or a video

• Books: “Tuesdays With Morrie”, “The Notebook”

• Movies: “Still Alice”

• Videos: Visit the “AdvanceCarePlanning” YouTube channel and watch the “ACP Conversations Video” to see how others have had the conversation.
Questions to ask yourself when starting your conversation on advance care planning:

Who do I want to talk to?

Who else?

- Partner/Spouse
- Child/Children
- Mom
- Dad
- Caregiver
- Doctor
- Friend
- Spiritual leader
- Other

When is a good time to talk?
Think about when you might approach your loved ones. For example, the next big holiday, at Sunday dinner, before your next big trip, before a child goes to college or a baby arrives.

Where is a good time to talk?
Think about where you might have the conversation. For example, at the kitchen table, the cottage, a café/restaurant, on a drive or walk, in a place of worship.

What do I want to be sure to say?
List the most important things you want to talk about during your conversation.
Step 5

Step 5: RECORD

Writing down or recording your plan makes it easier for others to understand what's important to you, and to make decisions for you if you couldn't speak for yourself.

This workbook can be used to document your wishes, but you may also choose to create your own plan or use a form provided by a legal or health professional. Please go to acp.truenth.ca to check out the legal requirements in your province/territory. You could also make a recording or video of your wishes.

My Other Planning Documents:

In addition to this document, I have also completed the following documents:
(check all that apply, and note the location of each)

☐ Will...................................................Location: .............................................................
☐ Power of Attorney (financial)......Location: .............................................................
☐ Organ Donation..................................Location: .............................................................
☐ Other (e.g., specific bequests, etc.)
  Name of document: ..................................................Location: .............................................................

Other wishes and thoughts
Write down anything that would help others understand and support you at the end of life.

Congratulations on taking the first step!
If you have recorded your wishes, give a copy of it to your substitute decision maker(s), family members, doctor, nurse practitioner, and any other health or legal professionals.

Most importantly, talk to your substitute decision maker(s) about your wishes. Remember, this person only speaks on your behalf if you are unable to speak for yourself.

Remember, to review and revise your wishes
  • When there are life changes
  • When there is a change in your health status
  • When new information is available
  • Annually
Appendix

Allow natural death refers to decisions NOT to have any treatment or procedure that will delay the moment of death. It applies only when death is about to happen from natural causes.

Capacity

Being capable means:

- You must be able to understand the information that is relevant about making a decision about your health care, nutrition, shelter, clothing, hygiene, safety
- You must be able to grasp the likely results of making the decision or not making the decision.

Capacity can be different for different decisions.

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to restart your heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest to electric shocks that restart the heart and machines that breathe for the individual.

Comfort measures: treatments to keep you comfortable (for example, pain relievers, psychological support, physical care, oxygen, etc.) but not to keep you artificially alive or cure any illnesses.

Consent

- Health care providers must get consent or refusal of consent to any treatment
- Consent includes agreeing to, withholding or withdrawing treatment
- Wishes are not consent
- Wishes are commonly “What if” statements

Dialysis is a medical procedure that cleans your blood when your kidneys can no longer do so.

End-of-life care refers to health care provided at the end of a person’s life. This type of care focuses on you living the way you choose during your last days or weeks and on comfort measures until the time of death.

A feeding tube is a way to feed someone who can no longer swallow food.

Health care provider / Health care professional describes a person licensed, certified, or registered in their province/territory to provide health care. For example: a doctor, nurse or social worker.

Informed consent refers to the permission you give to health care providers that allows medical investigations and/or treatments. Health care providers give detailed explanations of the investigations/treatments and their risks and benefits before you give verbal consent or sign a consent form.

An intravenous (IV) is a way to give you fluids or medicine, i.e. through a vein in your hand or another part of your body.

Life support with medical interventions refers to medical or surgical procedures such as tube feeding, breathing machines, kidney dialysis, some medications, and CPR. All of these use artificial means to restore and/or continue life. Without them, you would die.

Palliative Care is care provided for people who have a life-limiting illness that focuses on providing good quality of life. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support, both for you and for those who are helping to care for you. Palliative care often focuses on pain management and comfort.

Power of Attorney is a term that typically indicates someone who is legally appointed to speak on your behalf. There are different kinds of powers of attorney. A power of attorney for finances does not have the ability to make health care decisions on your behalf. Check the legal requirements in your province/territory at acp.truenth.ca

A Substitute Decision Maker is a person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf of another person when they are incapable of communicating their wishes on their own. This person might also be known as a medical proxy, a health representative or agent or a Power of Attorney for Personal Care.

Symptoms are signs that you are unwell - for example, pain, vomiting, loss of appetite, or high fever.

A terminal illness means an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.

A ventilator is a machine that helps people breathe when they cannot breathe on their own.