Advance Care Planning Workbook

Most people will develop a chronic progressive disease over a lifetime. That’s why it’s important to plan ahead for a time when you may not be able to make your own healthcare decisions.

This workbook can be used to help you develop your plan through conversations with your family, close friends, doctor or healthcare provider.
How to START Advance Care Planning

Think
about what’s right for you in the final days of your life.

Learn
about your medical condition and medical procedures. Some may improve your quality of life, while others may not.

Choose
your decision maker, the person who will make medical decisions for you when you cannot make decisions for yourself.

Talk
about your wishes with family, close friends, your decision maker, and healthcare provider and doctor.

Record
your wishes in writing, on video, or in any manner you choose.

Update
your plan when you change your wishes.

Remember,
it’s important to review your plan regularly to make sure it reflects your wishes, especially if something in your life changes.

Continue the conversation!

An Advance Care Plan does not need to be written. However, when your advance care plan is written it is called an Advance Directive.

An Advance Directive is used to document your care wishes so your chosen decision maker can refer to it when making care decisions for you in the future, if and when you can’t make decisions for yourself.
THINK About it

You have a lot to think about and it can be difficult to know where to start.

Who we are, what we believe and what we value are all shaped by experiences we have had. Religious commitments, family traditions, cultural values and customs, jobs and friends affect us deeply.

Has anything happened in your past that shaped your feelings about medical treatment?

Think about an experience you may have had with a family member or friend who was faced with a decision about medical care near the end of life. What was positive about that experience? What do you wish would have been done differently?

Among the important things to think about are your wishes for future healthcare in case you can’t speak for yourself. This is called Advance Care Planning.

Think about the past medical care a family member or friend has received at end of his or her life...

Did you feel that your family member or friend received excellent end-of-life care?

Were there things that could have been done better?

If you were planning for yourself, what would you do the same or differently?

Advance Care Planning is

- An opportunity to reflect on your values, beliefs and wishes for care.
- Conversations with family and friends to let them know your future health and personal care wishes in case you become unable to speak for yourself.
- A way to give your loved ones peace of mind in making decisions about your care and treatment during a difficult time.
- A chance for you to think about the way you want to live the final months of your life.

An Advance Care Plan does not go into effect until you are unable to make your own decisions. You can always change your mind about your care.

Your advance care plan may never need to be used. However, if your chosen decision maker needs to use it, he or she will appreciate knowing what quality of life is acceptable to you.
LEARN about your present health

“Advance care planning is like retirement planning — it is important to start early, even if you don’t need it for many years to come.” – Healthcare Provider

You might have a number of questions during your 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 medical condition and what to expect can help you decide what is most important to you. Here are a few general questions to help you learn more about your health and condition(s).

What impact will this disease (eg. heart disease, lung disease, kidney disease, diabetes, dementia, cancer) have on your life?

What are your options when your health gets worse?

Are the treatment and medication meant to cure your condition or just make you more comfortable or both?

Consider that in addition to your chronic disease, a more immediate situation might arise because of a serious illness or injury such as a car accident or a stroke. To plan for this type of situation, many people state: “If I’m going to be a vegetable, let me go” or “No heroics” or “Don’t keep me alive on machines.” While these remarks are a beginning, they simply are too vague to guide decision making.

What I need to ask my doctor and care providers about my health:

Is my illness curable?

Can you tell me how this disease progresses?

Can you tell me what I can expect from this illness? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?

How will this condition affect my ability to function independently?

What are some possible major changes in my health that my family and I should be prepared for?

In what way can I expect my health to improve (or not improve) if I choose this course of treatment, or another course of treatment?
CHOOSE your Decision Maker

When choosing a decision maker, it is important to think about these qualities:

Willingness to accept the role
Willingness to discuss and understand your goals, values and beliefs
Ability to make difficult choices
Willingness to honour and follow your plan

You need to completely describe to your chosen decision maker under what circumstances your goals for medical care should be changed from attempting to prolong life at all cost to allowing a natural death. When your condition has reached this point, some treatments and procedures may be harmful rather than beneficial because of the pain and suffering involved.

TALK about your advance care plan

Discuss with your family, friends, doctor or healthcare provider:

What gives your life meaning;

How do your decisions about your condition, your care and your treatment affect your loved ones;

If this changes the way you feel about your life;

What fears or worries you have regarding your condition.

Talk to your doctor or healthcare provider about what comfort care you would want and under what circumstances. These may include medication, spiritual, and environmental options.

Ask your doctor or healthcare provider to tell you which medical procedures may improve your quality of life, which will not, and why.

If your condition gets worse:

Do you have a preference regarding location of care? (For example, at home, in a healthcare institution.)

What spiritual values impact your healthcare decisions?

Do you have any fears, worries, concerns?

When would the burden of treatment outweigh the benefit of treatment? This question is very personal and only you can answer it.
In case of a serious illness or injury, there are a number of medical procedures called interventions, which can prolong life and delay death.

These interventions could include mechanical ventilation, tube feeding, intravenous fluids or other treatments.

It is important to think about your wishes for these types of medical procedures.

You may also have other wishes related to your care at the end of life – hearing a special piece of music or having certain spiritual rituals performed.

You can use the questions below to document your wishes for care. Talk to your doctor, your chosen decision maker and your healthcare provider to understand when these interventions might help or harm you.

What is most important to me in terms of my mental and physical health? (For example, being able to care for my own personal physical needs, recognizing others, communicating with others, being able to read or write, or think.)

What would make keeping me on life support or continuing life-saving treatment unacceptable for me? (For example, being unable to communicate, or interact with those around me, not having control of my bodily functions, little hope of ever getting better or I would always want to continue life support.)

When I think about dying, I worry about:

If possible, when nearing death, I would prefer to spend the last days and hours of my life at ........................................................................................................ with the following people at my bedside: ........................................................................................................
Your Advance Care Checklist

☐ I have thought about my life, what’s important to me, what I value about being alive, and what medical care I might accept or would refuse in the future when I can’t speak for myself.

☐ I have spoken to my healthcare provider(s) about my current health and what future healthcare decisions I might need to make.

☐ I have discussed my healthcare treatment wishes with my family and trusted friends.

☐ I have chosen my decision maker who understands and can support my wishes.

☐ My doctors and I have spoken together about my Advance Care Plan.

☐ I have discussed and completed an Advance Directive and given copies to my chosen decision maker and healthcare provider(s).

I have left a copy of my Advance Care Plan:

Please check all that apply

☐ On the refrigerator
☐ As part of my coordinated care plan
☐ With CCAC
☐ With my chosen decision maker
☐ With the hospital
☐ With my family
☐ With my primary care provider

NOTES
More Information:

The Ministry of the Attorney General of Ontario provides a booklet that will help you complete a Power of Attorney for Personal Care and for Property (finance). This allows you to choose the person you want to make decisions for you. You can obtain a copy from the Internet at

http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp

If you rather, you may call them at:

416-314-2800

or toll-free at: 1-800-366-0335 or TTY: 416-314-2687.

The link listed below provides answers to some important questions about preparing an Advance Care Plan/Living Will and/or Power of Attorney for Property or Finance.


Canada has a National Campaign to encourage all Canadians to think about preparing an Advance Care Plan. It is called “Speak Up”.

http://www.advancecareplanning.ca/

Advocacy Centre for the Elderly

www.advocacycentreelderly.org/