INTRODUCTION

Woody Allen said:

“I’m not afraid of death... I just don’t want to be there when it happens.”

The process of dying can be scary. Many of us think about dying in a vague way, hoping it will happen at home after a brief illness, without pain, surrounded by loving friends and family. In fact most Canadians don’t die that way. Too many of us die in hospital, tethered to machines, tagged to receive CPR even if we don’t want it. Fear causes us to avoid planning for health care at the end of life, and that can result in all sorts of problems. Planning in advance confronts those fears and increases our chances of a good death down the road.

All Canadians are guaranteed protections under their Charter Rights and Freedoms, 1982. The Charter provides for freedom of religion, of thought, of expression, of the press and of peaceful assembly. The question of a right to access physician assisted dying has thrust patient autonomy under law into the spotlight as it relates to claims that such restrictions violated sections 7 (the right to "life, liberty, and security of the person) and 15(1) of the Canadian Charter of Rights and Freedoms (equality). Another issue of consideration relates to a patient charter of rights. At this time no federal framework for patient rights exists. Individual provinces have led their own initiatives regarding rights and entitlements to Health Care including: Alberta, New Brunswick, Nova Scotia, Ontario and Quebec.

Planning ahead makes us think about our deep-seated values and the things that make our life worth living. It encourages us to imagine illnesses that could happen to us and figure out what treatments we would want, which we would refuse, and why. Planning causes us to think about our rights and preferences as individuals in a huge and complicated health care system, and to write our wishes down so that others will know what we want if we can’t speak because we are too sick.

Planning ahead makes the process of dying less scary.

This booklet is for you.
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INFORMED CONSENT

It’s your life, it’s your body. You have the right to direct what happens to it. You cannot receive medical treatment without your ‘informed consent’. At the same time, your physician has both a professional and a legal duty to involve you in decisions about your health care.

Informed consent means that you understand your diagnosis (the disease that you have) and prognosis (the likely course of your disease), and that you agree to the medical treatment proposed by your physician.

Your physician must explain the recommended treatment, whether there are alternatives, and why a particular treatment is better than others. Your physician must clearly explain the benefits as well as the risks, discomforts and possible side effects of the treatment, as well as the odds of its success or failure. You must also be told about the consequences if you refuse to be treated, but your physician cannot force you to accept a treatment if you do not want it.

Questions to ask your physician “How will I feel during and after?” “Will this make me better?” “I’m just not sure...is there someone else I can ask?”

Your questions are important and you should not be afraid to ask about anything that worries you. Sometimes the number of specialists involved and the treatments themselves can seem overwhelming, and discussions about your care can be emotionally difficult. Having a close family member or friend by your side when you discuss treatment options with your physician is a good idea.

Making important and often irreversible decisions about treatment requires trust and honesty between you and our physician. If you are unsure, if you have doubts, then you can ask for a second opinion. You may feel awkward doing this but a second opinion could ease your fears. A wise physician will understand your need for a second opinion and will make a referral for you.
Salvatore has incurable stomach cancer that causes him great pain. His physician recommends radiation therapy. Salvatore wonders if this treatment will cure him or just prolong his life and make him feel awful. Will radiation improve his quality of life? Will it buy him time to get his affairs in order? Salvatore would like to know more about the risks and side effects associated with the treatment. Accompanied by his wife, he meets with his physician to outline his worries.

The physician explains that radiation may slow the progress of the cancer and help to decrease the pain, and in any event only one radiation treatment will be needed. There will be few bad side effects. His physician notes that the only other option is refusing treatment altogether. It is up to Salvatore to decide.

Salvatore goes home and quietly discusses these options with his wife. He decides on the radiation, which does indeed reduce the pain. He is able to spend meaningful time with his family and friends and put his affairs in order before dying seven months later.
ADVANCE CARE DIRECTIVES

Advance care directives are health care instructions, written while you are well and able, just in case an accident or disease makes you unable to speak for yourself at some point in the future.

To write an advance care directive, you need to understand the rights and options available to you should you become ill or injured. You think about the treatments that you might want or not want in particular circumstances, and write it all down in a document.

Advance care planning guides are available online from End of Life Planning Canada, Dying with Dignity Canada, some provincial and territorial governments and some regional health authorities.

When you have completed your advance directive, sign it and make copies to give to your substitute decision maker, your physician, your spouse and your adult children too. Review the directive once in a while to make sure it continues to represent your health care wishes and preferences.

Remember that if you are able to speak for yourself, your verbal instructions will override any written directive you may have. Your advance directive is only used if you are so ill or injured that you cannot communicate decisions about your health care.
YOUR SUBSTITUTE DECISION MAKER

One of the most important health care decisions you will make is choosing your substitute decision maker. This is the person legally empowered to speak for you if you can’t speak for yourself. If you are unable to give your consent because you are in a coma or because of a disease such as Alzheimer’s, then your physician must obtain the consent of your substitute decision maker before beginning or withdrawing any medical treatment.

It is important that your substitute decision maker is someone you trust, who knows and understands your values, and who is prepared to make difficult decisions for you, such as stopping treatments that are keeping you alive.

You can appoint anyone that meets the specified criteria in your province to be your substitute decision maker if that person is willing and able to make health care decisions on your behalf. You can appoint more than one substitute decision maker, but all would have to agree on everything. Better to appoint a first choice and an alternate, just in case your first choice cannot be reached when needed.

You must complete and sign a formal legal document to appoint your substitute decision maker. Forms are available from your provincial government or from organizations such as End of Life Planning Canada and Dying With Dignity Canada. If you have not appointed a substitute decision maker, your province has a law that ranks the people who are legally entitled to give or refuse consent on your behalf, starting with your spouse, then your child, your parent, etc.
Kareena, 86, has advanced Alzheimer’s disease. She lives in the dementia wing of a nursing home in Edmonton. She no longer recognizes anyone, no longer speaks, eats only if spoon fed, and basically sits in a chair all day, staring blankly, oblivious to everything around her.

Kareena has two daughters. Her oldest daughter Amalia lives in Winnipeg. Her youngest daughter Sophie lives close by and visits regularly.

It is winter and Kareena gets pneumonia. Sophie calls Amalia to suggest a visit while mum is still alive. Because of their mother’s advanced Alzheimer’s, Sophie says she has refused antibiotics for their mother and will not let her be taken to the hospital. Amalia is outraged and accuses Sophie of trying to kill mum. Sophie counters that their mother would be horrified to see herself now, the sad shell of her former lively self. Amalia calls the head of the nursing home to demand that her mother be taken to the hospital so that physicians can save her life.

But Kareena has a valid advance care plan and a legal document that appoints her daughter Sophie as her substitute decision maker. The two had talked often about Kareena’s wishes, values and beliefs. Kareena’s advance directive clearly stated she would prefer to die naturally than to be ‘saved’ to live a severely debilitated life.

Despite pressures from her sister, and with deep sadness, Sophie refuses all treatment on behalf of her mother, who dies naturally of pneumonia the following week.
MEDICAL TREATMENT

If you are sick, you have the right to accept, refuse or discontinue medical treatments. Your physician will recommend what you should do, and is obliged to tell you if the decision that you make seems unwise. But your physician cannot force you to have a treatment that you do not want.

Legally, there is no difference between discontinuing a treatment that has already started and refusing it in the first place. When you accept to start a medical treatment, you are giving your consent. But you are entitled to change your mind and withdraw your consent at any time.

If you are a competent adult making an informed decision, your physician must respect your decision to refuse or discontinue a medical treatment, even if the treatment is keeping you alive. You have the right to refuse dialysis for example, or a ventilator, or nutrition through a feeding tube. You can refuse a blood transfusion.

Carolyn, 46, is a Jehovah’s Witness. She has lived in Regina and has had to manage a bleeding disorder all her life and more recently several bleeding episodes, although none so far that have been serious. But she could lose a significant amount of blood at any time, and that would require a blood transfusion to keep her alive. Because of her faith, Carolyn refuses to have a blood transfusion, even though she knows she could die as a consequence. Carolyn’s health care providers cannot legally give her a blood transfusion, even in an emergency. Aided by an elder of her church, she has talked to her physicians about her strong beliefs. She now carries an explanatory card in her wallet to ensure she won’t be given blood even in an emergency.

In an accident or an emergency, if you are unable to speak for yourself, life-saving treatment will begin because your consent is implied. If you feel strongly that you do not want life-saving treatment even in an emergency, carry with you a valid advance directive that clearly states your wishes.
CPR and DNR Orders

CPR is a medical procedure designed to restore normal heartbeat if your heart suddenly stops working. It can involve manual chest compressions or electric shock paddles. CPR can save your life in an emergency, but the success rate of CPR for seriously ill or frail seniors is very low, and if you survive CPR the odds of permanent damage from the procedure itself are high.

It is important to think ahead about CPR and to make your wishes known to your family and your physician. In an emergency, first responders will automatically start CPR when they arrive because your consent to treatment is implied.

You can prevent CPR by getting a Do Not Resuscitate order (DNR) whether you are in a hospital or living at home. A formal written DNR order by your physician instructs other health care providers to withhold CPR if your heart stops beating. Your physician must make sure that you are capable of making an informed decision about DNR after discussing the risks and benefits involved. Each province and territory has different rules and requirements concerning DNR orders, and getting the correct form can be a challenge. Talk to your physician about this.

Martha, 94, is a widow living in a long-term care home in Hamilton. She is an avid reader and looks forward to doing the daily crossword. While her mind remains sharp, Martha is very frail and needs help with dressing, bathing and toileting. She has had a full and meaningful life and is ready to die naturally whenever the time comes. She doesn’t want CPR if her heart stops beating. Martha asked her physician if she should have a DNR order tattooed on her chest, or if there are better ways to ensure her wishes are respected.

After discussing risks and benefits with her, Martha’s physician completed and signed an official, numbered, non-transferable Do Not Resuscitate (DNR) order that instructs medical personnel and emergency responders not to administer CPR in the event of cardiac arrest. Martha’s physician reviews this decision with her periodically to ensure that she has not changed her mind. Martha has told her two children and the staff at the long-term care home about her decision, and has given them copies of the DNR order.
As a competent adult, you can decide to stop medical treatments that are keeping you alive, even if your physician thinks this is a bad idea, and even if your decision will hasten your death. Your physician has a professional duty to tell you what to expect if you choose to discontinue a particular treatment, but the physician must respect your informed decision, whatever it is.

The decision to refuse further treatment is emotionally difficult. Regardless, your decision to stop life-prolonging treatments is both ethical and legal, and it can be a rational decision for you, based on your own personal circumstances.

Raynald, 83, a widower, lives in a retirement home in Vancouver. For the last four years, three times each week, paratransit has taken him to and from the dialysis centre at the local hospital. The drive plus several hours of dialysis take up most of the day. His eyesight isn’t what it used to be. He is always tired, too tired to participate in group activities at his residence. He misses his wife. His children and grandchildren visit every Sunday but otherwise his life consists largely of TV and dialysis. Raynald knows that kidney failure would normally have killed him several years ago and that only dialysis is keeping him alive these days. He is beginning to doubt it is worth it. Raynald talks to his physician and learns that he can stop dialysis at any time after which he would likely die within a week. Knowing this gives Raynald a feeling of control over his life. He makes the informed decision to stop dialysis on the anniversary of his wife’s death, three months hence. He does not tell his family as they would be distraught. He ensures his affairs are in order and enjoys the remaining days with his family. On the appointed day, he stops going to dialysis and five nights later he dies peacefully in his sleep.

While you have the right to stop your own life-sustaining treatments at any time, your physician does not have the right to withdraw life-sustaining treatments from you unless you consent to it. If you are not able to speak for yourself, for example if you are in a coma, then the consent of your substitute decision-maker is required before life-sustaining treatments such as a feeding tube or a ventilator can be removed.
Nutrition and hydration by tube are considered medical treatments. You have the right to refuse them in the first place, or to stop them when they have started.

You also have the right to refuse to eat or drink, or to be fed or given drinks by others. This is referred to as Voluntary Stopping of Eating and Drinking (VSED) and is a decision supported by many palliative care providers. It is not an easy way to die, and medical aid to die may be a better option for some who wish to hasten their death.

George, 78, is a dairy farmer. He lives with his wife in a lovely stone farmhouse not far from Moncton. He has lived there all of his life. He has complications from diabetes and his condition is worsening. He has a heart condition, his swollen legs make it difficult for him to get around and now he is in constant pain from a severe infection in his right foot.

His physician recommends surgery to remove his right leg below the knee. Without it, the infection will spread and he will die. George refuses the amputation. He does not want to spend the rest of his life in bed or in a wheelchair. He worries that his wife will be unable to care for him at home. He won’t move to a long-term care home. He doesn’t want to continue living in pain. He can no longer do the things that are important to him. He loves his life and his family but he comes to the sad conclusion that it is time to go.

George does not want to prolong the painful process of dying so decides to stop eating and drinking. His wife understands and supports his decision, but his children are horrified and try to talk him out of it. But George is determined and eventually the family agrees to respect his wishes, for which he is grateful.

Arrangements are made for home nursing and his physician arranges for sufficient medicine to control the pain and severe discomfort that George will have to endure. His wife and children surround him with love. George slips into a coma on the fifth day of his fast and dies two days later.
PAIN AND SYMPTOM MANAGEMENT

Pain hurts. It degrades quality of life by creating discomfort, distress or agony. Pain caused by diseases such as cancer can be unremittingly severe at the end of life. Physicians are getting better at understanding and managing pain. They have an ethical responsibility to do everything they can to control your pain.

Your physician will ask about any pain you are experiencing and will decide in consultation with you how best to control your pain.

Samuel is 76, he lives alone in an apartment in Halifax. He has an incurable lung disease. He suffers constant pain and shortness of breath, and is anxious much of the time. His physician is reluctant to give him stronger pain and anxiety medications because they could make his breathing worse and it is possible that he would die. Samuel argues that every breath he breathes is torture. He begs for better symptom relief, even knowing it might hasten his death. Recognizing that Samuel is making an informed decision concerning his treatment, his physician agrees to increase the pain-control drugs, even if this might hasten Samuel’s death.

Ann, 44, is a single mother. She was in a car accident that left her with severe back pain. She decided to have back surgery despite possible complications. The surgery itself was successful, however while in hospital she acquired an infection at the surgical site. Her physician induced a coma so her body could recuperate from the infection. Unfortunately, the type of infection has been hard to treat and continues to spread. Her family is devastated and they are desperate to keep her in ICU with full life support no matter the odds of her survival.
PALLIATIVE CARE

If you are facing a life-limiting illness, palliative care is intended to help you live as well and as comfortably as possible in the time you have left until death occurs naturally. The final stage of your life can be painful and scary and lonely. Palliative care offers physical, mental, emotional and spiritual support to help you and your family to navigate this difficult time with strength and dignity.

Palliative care is usually provided by a team that may include physicians, nurses, social workers and spiritual advisors. The palliative care team values your need to understand what is happening to you, and will have conversations with you and your family about your values and your care preferences to ensure that your final days are as good as they can be.

You should be able to get palliative care wherever you are - at home, in a long-term care residence, in a hospice or in a hospital. Palliative care is a good thing and is becoming more widely accessible in Canada.

Frank, 85, a widower whose wife died three years before, was rushed to hospital in Saskatoon when he collapsed at his retirement residence that morning. Wracked with pain from untreated stomach cancer that had spread to his liver, he had not eaten for several days. Now he was lying on a gurney in the emergency department. He could not go back to his residence because he was too sick. The hospital could not admit him because there were no beds available and in any event no treatment could cure his terminal cancer. His only daughter lived hundreds of kilometers away and could not care for him in a meaningful way.

A place was found for him at a local hospice, a ten-bed residence providing 24-hour care in a home-like setting. He arrived depressed and near death, but once the medical staff got his pain under control, his appetite returned, his mood improved, volunteers read to him and spent time with him, and his condition stabilized. His daughter was able to visit twice, staying in the family suite at the hospice. He died peacefully with her at his side twelve days later.
One of the major goals of palliative care is pain relief. Drugs today can control most of your pain so that it is tolerable, but nausea, coughing, shortness of breath and other agonizing symptoms can persist, causing continued anguish and distress for you and your family. In terminal situations where pain is unremitting and all other options have failed, it is medically and ethically acceptable for your medical team to turn to palliative sedation.

Palliative sedation drugs lower your level of consciousness to relieve intolerable symptoms. Palliative sedation can be intermittent to permit occasional periods of wakefulness and lucidity, in which case life-sustaining food and water will continue to be given. Or it can be continuous, where food and water are withheld. Continuous palliative sedation is only used in situations where suffering is so intractable that nothing else can relieve the pain, and where death is expected within a week or so. Palliative sedation can only be used after consultation with you, or with your substitute decision-maker. It can never be used against your will. The intention of palliative sedation is not to hasten your death, but to provide comfort in the final weeks or days of your life.

Ming, 67, was a history professor in Medicine Hat when she was diagnosed with a brain tumor. The disease advanced quickly and Ming was admitted to the palliative care program at the hospital when her physicians concluded she would die soon. Although her mind was sharp, Ming was bedridden, enduring serious pain along with compromised vision and hearing. Paralysis would soon set in. Because there was no other way to relieve her intolerable pain, Ming received palliative sedation. Physicians controlled the level of her drugs and over a period of two weeks they occasionally brought her back to a state of consciousness so that she could spend short periods of lucidity with her family. Ming had discussed with her family and the palliative care team that she did not want to extend the process of dying. Her disease was terminal and she would never recover. At her request, and with the consent of her husband, her feeding tube was removed and she was put under continuous sedation. In her weakened state, Ming died peacefully three days later.
In February 2015, the Supreme Court of Canada struck down the prohibition in the Criminal Code against physician-assistance or medical aid in dying, that is having someone help you end your life. The ruling declared that a competent adult who: 1) clearly consents to the termination of life and 2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering intolerable to the individual in the circumstances of his or her condition, has the right to a physician-assisted death.

The right to a medically-assisted death will come into effect on June 6, 2016. Parliament, the provincial and territorial legislatures and various licensing bodies across Canada have analyzed the Supreme Court ruling and will regulate how best to implement the right to assisted dying in their respective jurisdictions.

The majority of Canadians favour assisted dying under certain strict criteria but there continues to be small but vocal opposition to this right. Only time will tell if access to assisted dying will be accessible to every Canadian who meets the stated criteria and requests an assisted death.

For some Canadians suffering greatly at the end of life, knowing that they can obtain an assisted death at a time and place of their own choosing may bring comfort to them, and the courage to persevere until death comes naturally.

For others, an assisted death may come as a blessed relief from a life of intolerable pain and suffering. Based on the experience of other countries that allow assisted dying, the number of Canadians who will take advantage of the right to an assisted death will likely be small.

Should you ever find yourself in circumstances that make you eligible for an assisted death, your decision to request assistance to die will be yours alone, based on what matters to you as an individual: your deep-seated values, your spiritual beliefs, your own set of circumstances. It will never be a decision that you take lightly.
PHYSICIAN ASSISTED DYING VIGNETTE

Paul, 54, a former marathoner and marketing professional, lives in Quebec with his partner Jerome. Paul was diagnosed 6 years ago with amyotrophic lateral sclerosis (ALS) after seeking genetic testing due to several family members dying terribly from the disease. While ALS is not inherited most of the time, it was in his case. At first Paul only gradually experienced some of the common symptoms of ALS including: painless, progressive muscle weakness. This meant that he could no longer train the way he used to and over time he suffered more severe muscle cramps and twitches and significant fatigue in his arms and legs making it impossible to run another marathon.

Recently, Paul’s breathing muscles have become affected. He is having troubling swallowing and Jerome has taken significant time off work to provide Paul’s care—but he does so out of tremendous love he has for his life partner of 22 years.

Paul’s speech is already worsening and he will soon need permanent ventilatory support to assist with his breathing. He has always been an ardent believer in individual freedoms and choice and so when death with dignity became a possibility with the landmark legislation of Carter v. Canada he knew that it would be something he wanted to explore.

Paul and Jerome discussed a physician-assisted death with their primary care physician. At first Dr. Frank said she needed time to think about it, she felt uneasy about the idea. Paul and Jerome received help from a national charity that guided them in how to have a better conversation with their family and with their physician. They explained that Paul wanted to pursue this option before his body completely wasted away and before he lost all control over his breathing or his muscles. Paul felt his quality of life was already worse than he’d ever imagined.

After a two-month period of discussing the option, their families gave their full support. It was a huge decision for Paul, and it was tough for the family at first. But they wanted to respect his wishes and knew he wanted to end his suffering surrounded by those he loved most.
As we age, it becomes increasingly important to consider what a good death will look like for us and for those we care for. No matter our age, it is always helpful to be informed and to start planning ahead.

For many of us, what matters most is the individual freedom to make our own choices, even if that means accepting a certain degree of risk. What happens to our bodies and the choices we make about our care are just as important when we are young as when we are nearing death. Depending on our stage in life, we may change our values and our vision for the kinds of interventions we would want, but being better informed can help every one of us at every stage of decision-making.

Most elderly people in their last year of life see a significant increase in aggressive care, including multiple hospitalizations. But most of us do not want to die this way, in hospital, tethered to machines that simply lengthen the process of dying. One way to improve the future is to plan ahead and become more informed about the rights and options that we have as individuals navigating our way through the health care system.

Become an advocate for your own health by learning about the professionals who will be involved in the delivery of your care, the processes surrounding your treatment and the likely outcomes of their interventions.

Remember…it is your right to decide what treatments you receive, or not, when you need medical care at the end of life.
ABOUT END OF LIFE PLANNING  CANADA

Our Mission
End of Life Planning Canada is a national charitable organization. Our mission is to help Canadians to navigate the end-of-life experience with confidence and dignity.

Our Mandate
We promote research and provide information, education and support to help individuals and their families to plan for a gentle and dignified death, and to navigate the health care system with confidence that their rights and preferences will be respected to the very end.

We offer a broad program of information, education and support about health care rights and options at the end of life. We:

- Encourage Canadians to think about their wishes for end-of-life care, to understand their options for achieving those wishes, and to make their preferences known to their families, caregivers and health care providers in the event they should become unable to speak for themselves in the future.
- Educate Canadians about legal rights and options at the end of life, to promote informed decision-making and improve the quality of their interactions with the health care system.
- Provide personal, confidential support to individuals and/or their families who wish to discuss end-of-life rights, options and preferences in a safe and compassionate place.
- Develop resource materials such as patient rights booklets and advance care planning kits tailored to each province and territory, and conduct seminars, discussion groups and workshops to offer practical advice on how to plan for a gentle and dignified death.

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**OTHER RESOURCES**

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*All provinces and territories (except for New Brunswick and Nunavut) have some form of advance directive legislation.

**The links on this page may become inactive or may change at a later date; we will strive to keep this document as up to date as possible; please visit www.elplanning.ca for the most up to date resources.*