PATIENT RIGHTS GUIDE

IT'S YOUR LIFE. IT'S YOUR CHOICE.

DYING WITH DIGNITY CANADA

YOUR HEALTH AND END-OF-LIFE CARE RIGHTS AND OPTIONS IN CANADA

This guide is a source of information for individuals who are eligible for publicly-funded health services in Canada – including Canadian citizens and permanent residents, collectively referred to in this guide as "Canadian residents."

In Canada, health care is managed by the provincial and territorial governments. This guide offers general information about patient rights in Canada, although some laws and procedures may vary by location.

Any reference to 'you' in the guide refers to yourself or, if you are incapable of making or communicating your own treatment decisions, your Substitute Decision-Maker.

The definition of 'mature minors' varies by location. Please refer to the definition as set by your province or territory if you are a mature minor or supporting a mature minor with their patient rights.

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INTRODUCTION

This guide was developed to inform Canadian residents of their rights as patients in the health care system, especially as they relate to rights and options at the end of life. The best time to review information like this is before you require health care; however, this knowledge is useful at any time. Understanding your rights as a patient is empowering and will help you make informed decisions about treatments and medical procedures.

Being informed helps us think about our values and consider what quality of life means to us. It encourages us to think about our wishes in the event of future illness, and what treatments – if any – we would want. Once we understand our rights, we can record our wishes and share them with our loved one(s) and health care provider(s). This will let others know what we want if we can't speak for ourselves or don't have the capacity to make our own health care decisions.

As a patient in Canada, you have the right to:

- Health care services without discrimination
- Understand your health condition and the treatments available to you
- A second opinion
- Have your Advance Directive*/prior capable wishes respected
- Have the authority of your Substitute Decision-Maker recognized
- Accept, refuse, or discontinue medical treatments, and to change your mind at any time

*The term Advance Directive may not be used or may be different depending on the province or territory in which you live.

- Decline cardiopulmonary resuscitation (in accordance with a DNR order)
- Refuse nutrition and hydration by artificial means or any other aspects of care
- Pain and symptom management
- Palliative care (including palliative sedation) if it is appropriate for your condition
- Request an assessment for medical assistance in dying (MAID)
- View, obtain, amend and limit access to your own health record

HEALTH CARE SERVICES IN CANADA

You have the right to health care services in Canada without discrimination based on grounds set out in the applicable human rights code, or rights under the Canadian Charter of Rights and Freedoms.

Canada has a publicly funded health care system. Under this system, Canadian residents have reasonable access to medically-necessary hospital and health care services without paying out-of-pocket. However, instead of having a single national plan, we have 13 provincial and territorial health care insurance plans. This is why health care laws and procedures may vary by location.

Roles and responsibilities for health care services are shared between provincial and territorial governments and the federal government.

The **provincial and territorial governments** are responsible for the management, organization and delivery of health care services for their Canadian residents.

The **federal government** is responsible for setting and administering national standards for the health care system through the Canada Health Act, providing funding support of provincial and territorial health care services, supporting the delivery of health care services to specific groups and providing other health-related functions.[1]

The *Canada Health Act* is Canada's federal funding legislation for publicly funded health care insurance. Outlined in the Act is the primary objective of Canadian health care policy – to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers.

[1]https://www.canada.ca/en/health-canada/services/canada-health-care-system.html

INFORMED CONSENT

You have the right to understand your health condition and the treatments available to you.

You cannot be forced to undergo medical treatment without your informed consent, except during emergency situations (see cardiopulmonary resuscitation and do-not-resuscitate orders, page 12). Your health care provider has both a professional and a

legal duty to involve you in decisions about your health care, and to obtain consent from you – or from your Substitute Decision-Maker (see page 9) in the event of your incapacity – before treatment (subject to care in an emergency).

Informed consent requires honesty and trust in the communication between you and your health care provider(s). It requires that you voluntarily agree to the treatment(s) proposed, and that you understand:

- Your diagnosis (the disease or condition that you have)
- Your prognosis (the likely course of your condition)
- The treatment options available
- The risks and benefits of the proposed treatment(s)

Your health care provider must explain the recommended treatment, any possible alternatives, why a particular treatment is better than others, and the likely outcomes if you choose a different treatment or no treatment at all. Your health care provider must clearly explain the benefits as well as the risks, discomforts and possible side effects of the treatment, and the odds of its success or failure. Your health care provider cannot force you to accept a treatment if you do not want it.

Here are some questions to ask your health care provider when obtaining informed consent:

- What are the potential consequences or side effects of this treatment?
- How will I feel during and after the procedure?
- Can you refer me for a second opinion if I wish? (See Second opinions, page 6)

Your questions are important, and you should not be afraid to ask about anything that concerns you. Sometimes the number of specialists involved and the treatments can seem overwhelming. Discussions about your care can be emotionally difficult. You have the right to have a family member, friend, or any other person you choose by your side when you discuss treatment options with your health care provider. (See Support person, page 10)

SECOND OPINIONS

You have the right to a second opinion.

Making important decisions about treatment requires trust and honesty between you and your health care provider. If you are unsure, have doubts, or just want further information or assessments regarding a health matter, you can ask for a second opinion. You may feel awkward doing this, but a second opinion could help clarify your situation and address your concerns. A wise health care provider will understand your need for a second opinion and will make a referral for you. And remember, you always have the right to change your mind about the chosen treatment.

How to broach the subject:

- I'd like to make an informed decision about my condition. Is there another specialist I could speak to?
- I'd like a second opinion about my case so I can be certain I am making the right decision and fully understand my options.

If your health care provider refuses to provide a referral, you can approach another provider for a referral. Each province and territory has their own referral recommendations or policies.

ADVANCE DIRECTIVE*

You have the right to express and document your wishes for your future care, and to have those wishes followed, provided that they are clearly stated, within the current law, and appropriate to your medical condition.

Each province and territory has their own requirements and documents for setting out health care wishes. This is sometimes referred to as an Advance Directive. An Advance Directive is instructions for your future health care that you document for use in the event of an accident or medical condition that leaves you without the capacity to make your own decisions.

Not all provinces and territories have laws that permit creating a legally enforceable Advance Directive. This is outlined in more detail in the free DWDC **Advance Care Planning Kit**. Even if your province or territory does not permit an Advance Directive, you can always provide a document to your Substitute-Decision Maker(s)

*The term *Advance Directive* may not be used or may be different depending on the province or territory in which you live. All of this is outlined in DWDC's Advance Care Planning Kit.

to assist them in acting on your behalf. You can also consider setting out your written wishes for care in Power of Attorney documents, and of course, should always discuss your wishes with your Substitute-Decision Maker(s).

To write an Advance Directive, you must first consider your values, beliefs and preferences for future health care. It is important to understand your rights and the treatment options available to you should you become ill or injured.

You can obtain a free **Advance Care Planning Kit** from Dying With Dignity Canada to guide you through the process of creating an Advance Directive. Many regional health authorities and provincial Ministries of Health also offer Advance Directive documents and planning guides.

TERM	DEFINITION
Advance Care Planning Kit	A guide to preparing your Advance Directive
Advance Directive*	A document stating your wishes for future health care should you not be able to speak for yourself.
Power of Attorney document	A legal document giving one person the power to act for another person.
Substitute Decision-Maker*	A person legally empowered to make health care decisions for you if you do not have the capacity to do so.

*Terms vary by province/territory

SUBSTITUTE DECISION-MAKER

In almost all locations, you have the right to appoint a Substitute Decision-Maker (SDM) for future health care decisions and to have the authority of your SDM recognized.

Each province and territory has their own term and requirements for a Substitute Decision-Maker (SDM); not all provinces and territories have laws that permit appointing an SDM. This is outlined in the free DWDC **Advance Care Planning Kit**. The forms are tailored for each province and territory, so be sure to use the right form for your jurisdiction and to read the instructions carefully.

One of the most important health care decisions you will make is choosing your SDM. This is the person legally empowered to make health care decisions for you if you do not have the capacity to do so. If you are unable to speak for yourself, either temporarily or permanently (for example, because you are in a coma or because of a disease such as dementia), your health care provider(s) must obtain consent from your SDM before beginning or withdrawing any medical treatment. The SDM is obligated to follow instructions provided in your Advance Directive and to make decisions in accordance with your prior capable wishes. However, even if you have an Advance Directive, appointing an SDM is important because it is unlikely that the Advance Directive addresses all medical situations.

It is critical that your SDM 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), in accordance with your prior wishes.

Your SDM does not need to be a family member. You can appoint anyone who meets the specified criteria in your province or territory if that person is willing and able to make health care decisions on your behalf. Refer to DWDC's **Advance Care Planning Kit** for more information on SDMs.

If you have not appointed an SDM, every province and territory has laws that prioritize the people who are legally entitled to give or refuse consent on your behalf, typically starting with your legal guardian (if any), your Attorney for Personal Care named in a document, spouse, then children, etc.

SUPPORT PERSON

You are entitled to have a support person by your side when you discuss treatment options with your health care provider(s). A support person is someone you choose, while you are still competent, to support you through your health care experience.

Having a support person can be helpful if, for any reason, you have difficulty navigating the health care system or stating your feelings and concerns. Having a support person is particularly important if you have difficulty hearing, understanding, or remembering what your health care provider tells you; or if you are anxious or experiencing

symptoms (like pain or nausea) that can make it difficult to concentrate and manage your health care alone.

Choose someone you are comfortable talking with and whom you can trust. In some provinces and territories, there are formal processes that allow you to provide written permission for your support person to access your medical information and assist you with managing your care.

TREATMENT OPTIONS

You have the right to accept, refuse or discontinue medical treatments, and to change your mind at any time.

You have the right to accept, refuse or discontinue medical treatments, and to change your mind at any time. Your health care provider is required to explain your options and make recommendations for your best course of action as part of the informed consent process (See Informed consent, page 4). Your health care provider may express that the health decision you make is unwise in their opinion; however, they cannot force you to accept a treatment that you do not want.

Some common treatment options and decisions in the context of end-of-life decision-making are discussed in more detail in the following sections.

CARDIOPULMONARY RESUSCITATION AND DO-NOT-RESUSCITATE ORDER

You have the right to decline cardiopulmonary resuscitation (CPR). A formal do-not-resuscitate (DNR) order must be obtained through your health care provider in accordance with the specific requirements of your province or territory.

Cardiopulmonary resuscitation (CPR) is a medical procedure designed to maintain blood circulation if your heart suddenly stops beating. 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 people is very low.[2]

It is important to think ahead about CPR and to make your wishes known to your loved one(s) and your health care provider(s) as you will not be in a position to speak for yourself when such intervention is required.

If you decide against CPR, you can help avoid it by getting a do-not-resuscitate order (DNR) or No CPR order, whether you are in a hospital or living at home. A formal DNR order must be obtained through your health care provider. It instructs other

[2]https://pubmed.ncbi.nlm.nih.gov/32500916/

health care providers to withhold CPR if your heart stops beating. Let your caregiver(s) and loved one(s) know about a DNR order and display it somewhere obvious (e.g., on your fridge, in your wallet) to inform others of your wishes.

Your health care provider must make sure that you are capable of making an informed decision about a DNR order after discussing the risks and benefits involved. Each province and territory has different rules and requirements concerning DNR orders. Talk to your health care provider to ensure you have the right information and the correct form.

Note: In an emergency situation, if you do not have the capacity to make health care decisions and a valid DNR order is not easily available, Emergency Medical Responders have a legal and ethical duty to do whatever is immediately necessary to keep you alive, including CPR. If you feel strongly that you do not want life-saving treatment even in an emergency, make sure to obtain a formal DNR order in accordance with the requirements of your location. Carry it with you or place it somewhere in plain sight (e.g., the fridge) so emergency responders can be aware of your request; however, there can be no guarantee that it will be followed if it isn't easily accessible.

STOP TREATMENT

You have the right to refuse or stop any treatment at any stage of your health care, even if such refusal or withdrawal proves detrimental to your health or leads to your death.

Your health care provider must respect your informed decision to stop treatment. Legally, there is no difference between discontinuing a treatment that has already started and refusing it in the first place. Your consent should also be sought as to whether life sustaining treatments (e.g., a feeding tube) should be initiated; this is not the decision of the health care provider.

When you agree 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 have capacity to make health care decisions, you can decide to stop medical treatments that are keeping you alive, even if your health care provider disagrees, and even if your decision will hasten your death. Your health care provider has a professional duty to tell you what to expect if you choose to discontinue a particular treatment, but the health care provider must respect your informed decision, whatever it is, even if they do not think you are acting in your own best interest. You can refuse any treatment, such as

dialysis, a blood transfusion, a ventilator, or nutrition through a feeding tube.

The decision to refuse further treatment can be 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 personal circumstances.

While you have the right to stop your own life-sustaining treatments at any time, your health care provider does not have the right to withdraw life-sustaining treatments from you without your consent. If you are not able to speak for yourself – for example, if you are in a coma – then consent from your SDM is required before life-sustaining treatments, such as a feeding tube or a ventilator, can be discontinued.

VOLUNTARY STOPPING OF CARE (VSC)

People who wish to allow their life to end naturally sometimes refuse or discontinue care which includes health care to prevent or cure illness. This may be referred to as voluntary stopping of care (VSC).

VSC commonly involves stopping or refusing the following (although not everyone refuses all of these):

- Oral food and drink (see VSED, page 16)
- Respiratory support (oxygen, BiPap, C-Pap, ventilator)
- Regular changing of position
- Any other procedures that might prolong life[3]

[3]http://eol.law.dal.ca/?page_id=2475

VOLUNTARY STOPPING OF EATING AND DRINKING (VSED)

You have the right to refuse nutrition and hydration by artificial means.

In Canada, nutrition and hydration by tube are considered medical treatments. You have the right to refuse them in the first place, or to stop them after they have started.

You also have the right to refuse nourishment by mouth. Individuals with capacity for health care decisions are legally permitted to refuse oral nutrition and hydration in all provinces and territories across Canada. This is referred to as voluntary stopping of eating and drinking (VSED).

VSED is not a process that should be undertaken without careful consideration. It is a very difficult process that requires medication, support, and supervision by a health care provider. If this is something you are considering, please discuss with your primary care provider before taking any action. A health care provider will be able to speak to the risks and benefits of all options.

PAIN AND SYMPTOMS MANAGEMENT

You have a right to be kept comfortable, even if the necessary medications will hasten the dying process.

Pain affects quality of life by creating discomfort and, often, distress. Pain caused by diseases such as cancer can be constant and severe at the end of life. A health care provider can offer pain management and has an ethical responsibility to do everything they can to control your pain. Your health care provider will ask about any pain you are experiencing and will decide, in consultation with you, how best to control it.

PALLIATIVE CARE

You have the right to palliative care if it is appropriate for your condition.

Palliative care focuses on both pain management and optimizing quality of life. A person does not need to be dying or to be in the final stages of an illness to benefit from a palliative care approach, although eligibility for palliative care may vary by location. A palliative care approach can work to alleviate physical symptoms and discomfort.

It is also beneficial when considering emotional distress or spiritual needs of both the patient and those close to them.

Palliative care is usually provided by a team that may include physicians, nurses, social workers and spiritual advisors. The palliative care team supports you and helps you understand your condition and options. They will have conversations with you and your loved ones about your values and your care preferences to ensure that your final days are as comfortable as they can be.

Palliative care and medical assistance in dying (MAID, see page 20) are not mutually exclusive. A person pursuing MAID may also receive palliative care and vice versa. However, MAID is currently prohibited at some hospitals, hospices and care facilities. If this is something you are considering, inquire about any restrictions that could impact your course of action.

Palliative care can be provided in different locations, including at home, in a long-term care facility, in a hospice, or in a hospital. Palliative care is becoming more widely accessible in Canada. Ask someone on your health care team about palliative care options in your region.

PALLIATIVE SEDATION

You have the right to receive palliative sedation if you or your SDM consent and your clinician deems it appropriate for your condition.

In terminal situations where pain or other intolerable symptoms are constant and all other options have failed, with your consent, your medical team may suggest palliative sedation in accordance with medical protocols. There are many medications that can control pain and reduce discomfort; however, suffering such as nausea, coughing, shortness of breath, and other difficult symptoms can persist in addition to pain. This can cause continued anguish and distress for you.

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 food and water may continue to be given if you want them. Or it can be continuous, where food and fluids are withheld (although, very rarely, intravenous fluids may be administered). Continuous palliative sedation is only used in situations where suffering is so intractable that nothing else can relieve the pain, and where death is anticipated soon – usually within two weeks. Palliative sedation can only be used after consent from you or your SDM, although it is your health care provider who determines eligibility for palliative sedation.

Palliative sedation can never be implemented against your will. Its intent is not to hasten your death, but to provide comfort in the final stages of your life.

MEDICAL ASSISTANCE IN DYING (MAID)

You have the right to receive medical assistance in dying (MAID) if you request it and you meet the eligibility criteria outlined in the Criminal Code.

Medical assistance in dying (MAID) occurs when, after you have met the eligibility criteria and with your consent, a physician or nurse practitioner provides or administers medication that intentionally causes death. MAID is now permitted, under the Criminal Code, for competent adults who request it and meet the designated criteria.

In Canada, two types of MAID are permitted:

- A physician or nurse practitioner can directly administer a substance that causes the death of the person who has requested it, or
- A physician or nurse practitioner can give or prescribe to a patient a substance that they can self-administer to cause their own death (not available in all provinces and territories, please refer to the options in your region).

Who is eligible for MAID under Canadian law?

Two independent physicians or nurse practitioners need to evaluate an individual in order to determine whether they qualify for MAID. To qualify, a person must satisfy all of the following criteria:

- Be eligible for government-funded health insurance in Canada
- Be 18 years of age or older and have decision-making capacity

- Have a grievous and irremediable condition*
- Have made a voluntary request for MAID that was not a result of external pressure
- Give informed consent to receive MAID after having received all information needed to make this decision, including a medical diagnosis, available forms of treatment, and options to relieve suffering (including palliative care).

***In order to have a "grievous and irremediable medical condition," a person must:**

- Have a serious illness, disease or disability (excluding a mental disorder until March 17, 2027, when the legislation is scheduled to change)
- Be in an advanced state of decline that cannot be reversed
- Experience intolerable physical or mental suffering from an illness, disease, disability or state of decline that cannot be relieved under conditions that the person considers acceptable.

You must be the one requesting MAID; your SDM cannot request MAID on your behalf.

You can discuss MAID with your health care provider and/or your local health authority, or you can contact Dying With Dignity Canada for more information.

ACCESSING YOUR HEALTH RECORDS

You have the right to see, obtain copies, and correct the information in your own health (medical) records.

Your medical records include facts about your health, your health care history (e.g., treatments and surgeries), your family history, and the care you are receiving (or have received).

Some reasons that you might want to review this information include:

- To learn about your health care history and treatments recommended or received
- To give health information to another provider
- To bring the information with you for a second opinion or additional care
- To gain information for life or health insurance purposes
- To file a complaint against a health care provider
- To ask for a correction or addition, if something in the record is incorrect or incomplete
- To request that your personal health information NOT be shared with others, such as family, friends, and health care providers

Your personal health information is protected by privacy laws which differ by location. For specifics, please consult the requirements of your location.

CONCLUSION

What happens to our bodies and the choices we make about our care are just as important when we are nearing death as they are when we are young. As we age, it becomes increasingly important to consider what a good death will look like for ourselves and for those we care for. No matter our age, it is always helpful to be informed and to plan ahead.

For many of us, what matters most is the individual freedom to make our own choices, based on our values and our definition of quality of life. Our values and vision for end-of-life will change over time. It is important to remain informed, update our records, and continue conversations about end-of-life choice and care.

It is also important to choose an SDM and to ensure that they know your health care wishes in the event of your incapacity.

Become an advocate for your own health by writing your own Advance Care Plan (or otherwise documenting your wishes) and keeping it up to date. And, continue to have ongoing conversations about your health care wishes with your SDM.

Remember, you have rights and options when it comes to your health care. You have the right to:

- Health care services without discrimination
- Understand your health condition and the treatments available to you
- A second opinion
- Have your Advance Directive*/prior capable wishes respected
- Have the authority of your Substitute Decision-Maker recognized
- Accept, refuse, or discontinue medical treatments, and to change your mind at any time
- Decline cardiopulmonary resuscitation (in accordance with a DNR order)
- Refuse nutrition and hydration by artificial means or any other aspects of care
- Pain and symptom management
- Palliative care (including palliative sedation) if it is appropriate for your condition
- Request an assessment for medical assistance in dying
- View, obtain, amend and limit access to your own health record

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