

REFUSING HEALTH CARE: What are my Rights?

THIS FACT SHEET DISCUSSES THE LAW IN BRITISH COLUMBIA THAT GOVERNS GIVING, REFUSING AND WITHDRAWING CONSENT FOR HEALTH CARE

Can I refuse health care?

YES You may refuse health care that is offered to you. The *Health Care Consent and Care Facility Admission Act* of BC states that if you are an adult (19 years or older), you have the right to refuse consent to health care that is offered to you by a health care provider.

Generally, as long as you are capable of informed consent, you have the right to make your own decisions about care.

This means:

- You can refuse or withdraw (stop) consent to health care for any reason, including religious or moral reasons, even if refusal will result in your death.
- · Your decision must be respected.
- Your refusal does not mean refusal to all treatment—giving or refusing consent is specific to the care or treatment offered at the time.
- You can change your mind.

EXAMPLE: Eric was diagnosed with prostate cancer. He consulted cancer specialists for advice about treatments. He was offered surgery to remove his prostate. He considered the risks and benefits and other opinions and decided not to have the surgery. He has regular check-ups with his family doctor and a cancer specialist (oncologist). Eric can decide to have surgery later, if it is still an appropriate treatment for the stage of his cancer. He can consent to other treatments for his cancer.

What does it mean to be capable of informed consent?

Different laws have different requirements about capability. The BC Health Care Consent and Care Facility Admission Act sets out requirements for being considered capable of giving or refusing consent to health care.

You are considered capable of making health care decisions, unless and until you demonstrate that you are incapable.

To determine capability, the doctor or other health care provider will try to determine if you understand two things:

- 1. The type of health care being offered—for example, its purpose and the risks—based on the information they provide, and
- 2. The fact that the health care is meant for you and your situation.

The health care provider must give you specific information about the care being offered to you including your diagnosis, the risks and benefits, and any alternatives. Also, the health care provider must allow you to ask questions and receive answers about the proposed treatment.

The health care provider must communicate with you in a way that fits your skills and abilities. They may allow your spouse, near relative or close friends who accompany you to help you demonstrate you understand informed consent. The health care provider cannot decide you are incapable only because of how you communicate.

To learn more, read the Nidus Resource Centre fact sheet on Health Care Consent: Your Rights and the Law

Can someone request medical assistance with dying on my behalf?

Medical Assistance in Dying (MAiD) is federal legislation (not provincial). MAiD has specific requirements about who is eligible. Only qualified health care professionals can confirm your eligibility to request MAiD and arrange for its administration. The Nidus Resource Centre produced a fact sheet about MAiD. A Representation Agreement covers many more situations than MAiD. It is essential to have a Representation Agreement; if you are capable, having a Representation Agreement does not prevent you from also applying for MAiD.

If I am incapable, can someone refuse care on my behalf?

A representative, named in your Representation Agreement, can give or refuse consent on your behalf. A Representation Agreement is the way to make your own arrangements for health care and personal care matters.

If you do not make your own arrangements, the law provides a default scheme to determine how health care decisions are made.



MAKE YOUR OWN ARRANGEMENTS

Representation Agreement Section 9

If you cognitively understand the nature and consequences of making a legal document to give someone authority to act on your behalf for health and personal care decisions, you may make a Representation Agreement section 9 in case you become incapable of informed consent in the future. A valid RA9 authorizes your representative to refuse or withdraw consent to life supporting health care care on your behalf—even if you might die as a result. (A representative can also give consent on your behalf.) A representative must make decisions according to your instructions, wishes and values.

Advance Directive

An Advance Directive does not authorize a person to make health care decisions on your behalf like a RA9. An Advance Directive is for writing instructions in advance about health care you do or do not want in case you become incapable of consent in the future, when the health care is offered. If you understand the type of health care your instruction deals with and the consequences of making a legal document to give or refuse consent, you may make an Advance Directive. You must also understand that if you have a stand-alone Advance Directive (without a RA9) your instruction will be followed directly by a health care provider. If your instruction does not apply to the specific circumstance or there is another reason it cannot be followed, the health care provider will select someone to be your Temporary Substitute Decision Maker

EXAMPLE: Gwen had a brain tumour and was scheduled for surgery. It was not cancerous and the surgeon said it would be easy to remove and only require about 5 days in hospital. Gwen made a Representation Agreement Section 9 with her friend Lori as the representative. She liked to be prepared. Before the surgery date Gwen started having seizures. No one knew why. After the second visit to the hospital, Gwen was admitted. She stopped breathing and was resuscitated and had her scheduled surgery. After the surgery, the doctor met with the representative and said that he had successfully removed the tumour but was unable to close Gwen's scalp because of swelling. He recommended removing parts of Gwen's brain that might be less critical in order to close the incision—otherwise she risked serious infection and would die. Gwen had told Lori, when she was first diagnosed, that she did not want parts of her brain removed. Lori refused the surgeon's proposed treatment—even if it meant Gwen's death. Click to read Gwen's story.

(see The Default Scheme). An Advance Directive has limited uses; it cannot cover as many types of decisions or situations as a Representation Agreement.

Representation Agreement Section 7

If an adult's mental or cognitive capability to make informed decisions about health care is already in question, they may make a legal document called a Representation Agreement section 7 (RA7). A valid RA7 that includes minor and major health care and personal care, gives your representative authority to give or refuse consent to health and personal care. However, they do not have the authority to refuse life-supporting health care. If such a situation arises, the health care provider will select someone to be a Temporary Substitute Decision Maker (see The Default Scheme). However, it is important to note that the RA7 can cover many end-of-life care decisions, including giving consent to medications for comfort and/or pain.

THE DEFAULT SCHEME

Temporary Substitute Decision Maker

If you do not make your own arrangements, or if there are gaps in your plan, the health care provider will select someone to be your Temporary Substitute Decision Maker (TSDM) according to a list in the *Health Care Consent and Care Facility Admission Act*. The TSDM list must be followed in a specific order starting with your spouse. It includes your next-of-kin or a friend or in-law, with the Public Guardian and Trustee (government official) as the last resort. The person selected as your TSDM can only refuse life support on your behalf if they know it is your wish or it is in your best interest AND the majority of the medical team believe it is medically appropriate. *Note*—Appointing your spouse or a parent or other person as your representative in a Representation Agreement gives them more authority to act on your behalf than they would as your TSDM. For more information, see Health Care Consent: How decisions are made if you are incapable

Committee of Person

Another imposed authority under the default scheme is Committeeship (adult guardianship). If you are determined incapable of making decisions about your health and personal care, a family member or friend may apply to the Supreme Court of BC to be appointed as your Committee of Person (guardian). If appointed, they take over your care decisions. Their duty is to make decisions according to what they think is best for you. Obtaining Committee of Person requires hiring a lawyer; it takes 3 to 4 months, costs around \$5,000 to \$7,000 (in 2015) and removes your civil rights. Committeeship is the last resort in BC because an adult may make an RA7 even if they are not able to manage their their own affairs.



Can a doctor refuse to give me life-supporting care?

Sometimes doctors may not offer treatment or health care in certain situations because they believe the situation is hopeless (futile). This might occur in an end-of-life situation and may fit with your wishes and your beliefs. In these cases, there is no need for you or a representative to refuse a treatment because no treatment is offered.

Unfortunately, some people with disabilities and the elderly have encountered situations where a doctor may not offer treatment because the doctor believes that the patient does not have quality of life—not because this is the patient's wish or preference or even medically appropriate. Sometimes a doctor might write No Cardiopulmonary Resuscitation (formerly called a Do Not Resuscitate Order) on a patient's chart. There is no law to back up a No CPR or DNR order as it is not a consent. However, such a notation is confusing, if not alarming, to patients and their supporters as well as to other health care providers.

EXAMPLE: Sharon is the representative in a Representation Agreement section 7 for her brother Lee who has a developmental disability. Lee was hospitalized recently and has been undergoing tests. He cannot talk but he is communicating distress and pain. He is experiencing other symptoms such as vomiting and diarrhea. As the representative, Sharon has the right to access information and records for her brother. She saw a notation for No CPR (DNR) on his medical chart. She immediately contacted the alternate and monitor named in the Agreement. Together they arranged for a meeting to let the doctor know that Lee has a full life, despite his disabilities and current health problems. Lee must receive access to the same care as any other patient in his condition and the No CPR notation must be removed as the doctor's opinion may be confused with Lee's right to health care and the law about consent.

Is a No CPR (DNR) form a way to refuse consent to resuscitation in advance?

The Ministry of Health and Doctors of BC (formerly BCMA) publish a No CPR form that family physicians can use to record their conversation with a patient. It is not a legal document and is not a consent, even if it is signed by the patient, or their representative or TSDM or court-appointed guardian. The No CPR form is a type of physician's order and is based on an old approach used before the health care consent legislation came into effect. Health Authorities are iusing a form called Medical Orders for Scope of Treatment (MOST), which is another type of physician's order. It is not a legal way to give or refuse consent.

A No CPR (DNR) form or MOST form, a living will/advance care plan, levels of intervention and Enduring Power of Attorney are not included on the list for health care consent as outlined below.

Consent for health care must be obtained when treatment is offered. Health care consent is only valid if given by the adult/patient/client or, if they are incapable, then obtained from an existing legal authority in the following order:

- 1. A Committee of Person (guardian) appointed by the Court (rare), or if none
- 2. A representative you authorized in a Representation Agreement (RA9 or RA7), or if none
- 3. An applicable instruction in an Advance Directive you made when cognitively capable to understand, or if none
- 4. A person selected by the health care provider from a list in the law to be your Temporary Substitute Decision Maker (TSDM).

Can a doctor withdraw life-supporting care without consent?

There may be some question as to whether the law in BC allows a doctor to withdraw life-supporting health care without consent. However, to be consistent with the principle of self-determination, which underlies the legislation, and in accordance with best practices, health care providers should obtain consent. If the patient is determined to be cognitively incapable to understand, consent to withdraw care may be given by a Committee of Person or if none, a representative named in a Representation Agreement section 9 or if none, an Advance Directive with an applicable instruction. As a last resort, a health care provider may select someone to be a Temporary Substitute Decision Maker.

Is there a Registry for my documents?

YES
You can store information and a copy of documents in the online Nidus Registry. The Nidus Registry provides secure storage and 24/7 access. You can manage the Nidus Registry account yourself and grant access to others who may need to know. The first step is to make your document(s) and then you can proceed to register.

When ready to register go to https://nidusregistry.ca Click Sign Up to create your Nidus Registry Account and make a registration. Once there is a Nidus Registry Account, you Log In to view and manage your registrations.



TIPS

Be sure to discuss your wishes and values with your representative and alternate in case they need to act on your behalf.

If you do not make a Representation Agreement, you will need to discuss your wishes with your spouse and all family members and friends in case one of them is selected to be your Temporary Substitute Decision Maker for health care. Your doctor or other health care provider may be able to give you ideas about some health care situations to consider, but they will not be called on to refuse or give consent on your behalf.

WHAT IS HEALTH CARE?

The definition of health care is wide ranging and includes surgery, medications, tests and taking part in approved research programs.

Health care takes place in many settings—including hospital, community, home, residential care and hospice. It may be offered by a number of different providers including doctors, nurses, dentists, physiotherapists, naturopaths—and others who are licensed or designated by provincial legislation.

REPRESENTATION AGREEMENT SECTION 9 OR SECTION 7?

A Representation Agreement is the only legal document in BC for authorizing someone to help you with health and personal care decisions. The authorities a representative can have are listed in section 7 and section 9 of the Representation Agreement Act. Each section also has capability requirements. An adult may make a RA7 even if they have cognitive difficulties.

A Representation Agreement section 9 (RA9) is for people who are cognitively capable now of informed consent and want to plan in case they become cognitively incapable in the future. It is a way to authorize someone to assist you or, if necessary, to make health and personal care decisions on your behalf, including refusing life supporting health care.

If you are assisting someone with health and personal care decisions because they currently have cognitive difficulties (their mental capability to understand is in question)—maybe due to a stroke, advanced dementia, brain injury or developmental disability—you can help them make a Representation Agreement section 7 (RA7).

Read more by clicking Representation Agreement Overivew

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RESOURCES

Nidus Resource Centre website - https://nidus.ca

- Find information on a variety of topics, FAQ and PDF fact sheets with more details
- · Under Information find videos and stories
- Find Forms for making a Representation Agreement and Related Forms like for revoking (cancelling) a legal document.
- Attend Events and sign up for newsletter

Look up **BC legislation** at www.bclaws.gov.bc.ca > Laws of BC > Public Statutes and Regulations > select letter of Act

When making your own arrangements, don't forget that you need to cover all four areas of your life as these are interrelated. The Nidus Resource Centre provides information on planning for health and personal care as well as for financial and legal affairs.