Can I refuse health care?

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 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.

What does it mean to be capable of informed consent?

Different laws have different requirements about capability. The *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 provided, and
2. The fact that the health care is meant for you and your situation.

The health care provider must provide you with specific information about the care being offered 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.

Read the fact sheet *Health Care Consent: Your Rights and the Law* to learn more.

Can I request help with dying when I am ready?

Federal legislation to amend (make changes) to the Criminal Code of Canada came into effect on June 17, 2016. This makes medical assistance in dying legal for individuals 18 years or older and under specific circumstances. You can read more at www.nidus.ca > Information > End-of-Life > Medical Assistance in Dying.

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

You can plan in advance and make your own arrangements. Planning is pro-active. If you do not make your own arrangements, the law provides a default scheme to determine how decisions are made.
**MAKE YOUR OWN ARRANGEMENTS**

**Representation Agreement Section 9**
If you 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 (RA9). A valid RA9 authorizes your representative with the same powers you have. They can refuse or withdraw consent to care on your behalf—even if you might die as a result. (They can also give consent on your behalf.) A representative must make decisions according to your instructions, wishes and values. An RA9 can cover personal care decisions (such as where you live, contact with others, diet or exercise) as well as health care decisions. Nidus has a free RA9 form on its website, see p. 4.

**Advance Directive**
An Advance Directive does not authorize a person to make health care decisions on your behalf like an RA9. It is for writing instructions in advance about health care you do or do not want in case you are incapable 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 an RA9) your instruction alone will be considered for consent 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 (see The Default Scheme). An Advance Directive has limited uses; it cannot deal with the unexpected. It also cannot cover as many types of decisions as a Representation Agreement; it does not cover personal care.

**Representation Agreement Section 7**
If an adult’s mental capability to make informed decisions about health care is already in question—due to an injury, illness or disability—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. Nidus has free RA7 forms on its website, see box on page 4.

**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. They cannot go by a list of preferred people that you wrote down in a planning booklet or gave to your doctor. The TSDM list must be followed in a specific order starting with your spouse. The list 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 other person as your representative in a Representation Agreement gives them more authority to act on your behalf than they would as your TSDM. Also, a TSDM does not have authority to make personal care decisions. For more information, go to www.nidus.ca > Information > Health Care Consent > More HCC Resources.

**Court-Appointed Decision-Maker**
Another imposed authority under the default scheme is through Adult Guardianship (also called Committeeship in BC). 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/Pesonal 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 court-appointed authority requires hiring a lawyer; it takes 3 to 4 months, costs around $5,000 to $7,000 and removes your rights—some call this civil death. It is also very difficult to reverse. Adult Guardianship/Committeeship is the last resort in BC because an adult may make an RA7 even if they are incapable of managing 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 view of quality of life. 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 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 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 form a way to refuse consent to resuscitation in advance?

NO 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. Fraser Health Authority is using a form called Medical Orders for Scope of Treatment (MOST), which is another type of physician’s order.

You will see that a No CPR form or other physician's order, 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 and as provided in BC law.

BC law requires that consent for health care 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 a legal authority in the following order:

1. A court-appointed decision-maker (committee of person/personal guardian) appointed by a juge (rare), or if none
2. A representative you authorized in a Representation Agreement, or if none
3. An instruction in an Advance Directive you made when capable and that applies to the specific circumstance, or if none
4. A Temporary Substitute Decision Maker selected by the health care provider.

Can a doctor withdraw life-supporting health 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 in all circumstances. If the patient is determined to be incapable, consent to withdraw care may be given by a court-appointed decision-maker or if none, a representative named in a Representation Agreement section 9 or if none, an Advance Directive with an instruction that applies to the specific circumstance. As a last resort, a health care provider may select someone to be a Temporary Substitute Decision Maker.

If I am incapable, can someone request a treatment to help me die?

NO The Criminal Code of Canada does not permit anyone to assist an individual to die if that individual is considered incapable of informed consent. Federal legislation came into effect on June 17, 2016 that allows an individual 18 years or older to request medical assistance with dying but they must be capable of informed consent when they make the request and when medical assistance to die is provided. For more information, go to www.nidus.ca > Information > End-of-Life > Medical Assistance in Dying.

Is there a Registry for my documents?

YES You can store information and a copy of your planning documents in the online Personal Planning Registry. The Registry provides secure storage with 24/7 access. You can manage the 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 it—www.nidus.ca/registry
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.

TIPS

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

Your doctor or other health care provider may be able to give you ideas about some health care situations to consider, but talking with them is not enough as they will not be selected to consent 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 or more of them is selected as your Temporary Substitute Decision Maker for health care if you are not capable.

REPRESENTATION AGREEMENT SECTION 9 OR 7

A Representation Agreement is the only legal document in BC for appointing someone to help you with health and personal care decisions.

A Representation Agreement section 9 (RA9) is for people who are considered capable of informed consent at the time of making their document. It is a way to appoint someone to assist you or, if necessary, to make health and personal care decisions on your behalf. Learn more and find forms at www.nidus.ca—click on the heading Planning on the Future Path.

If you are assisting someone with health and personal care decisions because their mental capability is in question today—due to a stroke, dementia, brain injury or developmental disability—you can help them make a Representation Agreement section 7 (RA7). Find forms at www.nidus.ca—for adults with a disability from birth or childhood, click on the first photo/heading; for adults whose capability was affected in adulthood such as stroke or dementia, click on the third photo/heading.

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RESOURCES

At www.nidus.ca > click Information
> Health Care Consent > More Resources
• How decisions are made if you are incapable
• Your Rights and the Law
• Restrictions on the Authority of a TSDM
• Notice for Major Health Care if a TSDM is selected
> Advance Directive Overview
> Adult Guardianship Overview
Watch the Nidus video on Getting Started
BC legislation can be viewed at www.bclaws.ca

When making your own arrangements, don’t forget that you need to cover all four areas of your life as these are interrelated. Nidus provides information on planning for health and personal care as well as for financial and legal affairs. Watch our videos at www.nidus.ca > Get Help > Videos

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