



Human Organ and Tissue Donation Act Information Guide

Nova Scotia Department of Health and Wellness

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Human Organ and Tissue Donation Act
Information Guide
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1. Background

The *Human Organ and Tissue Donation Act* (“HOTDA” or “the Act”) was passed by the Nova Scotia government on April 12, 2019. It was proclaimed on June 30, 2020 and will go into effect on January 18, 2021.

The Act will help increase organ and tissue donation in Nova Scotia by changing the way donation works in Nova Scotia. When it takes effect, the Act will mean that all Nova Scotians 19 and over, who are not exempt, will be considered for organ and tissue donation, unless they opt out.

Nova Scotians can register a decision to consent to donation of all or some organs and tissues (also called ‘express consent’) or opt out of donation. Those who do not register a decision will still be considered a potential donor, with a few exceptions. Under this legislation, their decision will be deemed or considered to have been given. This is referred to as deemed consent.

No changes will happen until the legislation takes effect on January 18, 2021.

2. Purpose

The purpose of this document is to provide information and guidance to Nova Scotians and health care practitioners on the Human Organ and Tissue Donation Act and consent to organ and tissue donation.

3. Overview

- 3.1. The Human Organ and Tissue Donation Act (“HOTDA” or “the Act”) was passed on April 12, 2019. It comes into effect on January 18, 2021 and deemed consent becomes operational on that date.
- 3.2. HOTDA addresses consent for both donation by a living donor (living donation) and donation after death (deceased donation).
- 3.3. HOTDA permits consent to donation to be deemed or presumed in certain situations.
- 3.4. Deemed consent applies only to deceased donation for the purpose of transplantation. It does not apply to living donation or to donation for scientific research or education purposes.
- 3.5. Deemed consent for transplantation purposes will not apply to everyone. There are exceptions in the Act for children, and adults who do not have mental capacity or who are not ordinarily resident in Nova Scotia.

- 3.6. People will still have a choice and can make their own decisions about donation after death. Decisions (consents, consent to specific organs or tissues and refusals) respecting donation after death are recorded in a Registry.
- 3.7. People are encouraged to talk to family members about their decision and their wishes around donation after death.
- 3.8. Family's role is not to overrule a person's decision about donation but they may provide information about the person's wishes if they are different than a recorded decision or deemed consent.

4. Registry

- 4.1. The Minister of Health and Wellness has designated the Nova Scotia Health Card Registry as the Registry to record consents and refusals respecting donation after death for transplantation under *Section 7* of the Act.
- 4.2. A person may record a consent or a refusal in the Registry. Recording a consent to donate is considered 'express consent'. Refusing to donate is also sometimes referred to as "opting out" of donation.
- 4.3. A consent may be registered for all organs and tissues or may specify which organs and tissues a person consents to donate. (*Section 8(2)* of the Act).
- 4.4. Nova Scotia Health Cards will indicate whether a person has consented to donate all organs and tissues (**Donor 1**), consented to donate specific organs and tissues (**Donor 2**) or has refused to consent (**opt out**).
- 4.5. A person may provide the information setting out their decision to **consent** to the Registry in the following ways:
 1. Completing a Nova Scotia Health Card application or renewal form.
 2. Contacting the Nova Scotia Health Card Registry by telephone at 1-800-563-8880 or 902-496-7008 in HRM.
- 4.6. During the period between Proclamation (June 30, 2020) and in effect (January 18, 2021), a person who wants to pre-record their decision to **refuse to consent (opt out)** to be effective on January 18, 2021, may do so in the following ways:
 1. Contacting the Nova Scotia Health Card Registry by telephone at 1-800-563-8880 or 902-496-7008 in HRM.
 2. Visiting www.novascotia.ca/organtissuedonation

- 4.7. After January 18, 2021 a person may provide the information setting out their decision to **refuse to consent (opt out)** to the Registry in the following ways:
 1. Completing a Nova Scotia Health Card application or renewal.
 2. Contacting the Nova Scotia Health Card Registry by telephone at 1-800-563-8880 or 902-496-7008 in HRM.
 3. Visiting www.novascotia.ca/organtissuedonation

5. Express Consent

Establishing Whether a Person Made a Decision During their Life

5.1 Registry

- 5.1.1. Prior to undertaking transplantation activities, the Registry must be checked to determine whether a decision has been recorded (*Section 10* of the Act). If a consent is recorded in the Registry, then deemed consent does not apply, and transplantation activities can proceed on the basis of that express consent to donate specified or all organs and tissues.
- 5.1.2. If a refusal (opt out) is recorded in the Registry, then deemed consent does not apply and the transplantation activities may not proceed unless family provide information to show the person has changed their mind (see *Section 5.2* of this guide).

5.2 Family

- 5.2.1. If a consent or refusal is recorded in the Registry, and a substitute decision maker provides information that a reasonable person would conclude that the person would have made a different decision than what is recorded in the Registry, then the substitute decision maker may give consent (express consent) or refuse on behalf of the person, in accordance with that information. (*Section 15* of the Act)
- 5.2.2. A substitute decision maker must provide the evidence they believe proves the person changed their mind.
- 5.2.3. The strength of various types of evidence ranges from the strongest evidence (a witnessed written document) to the least strong (oral, uncorroborated).
- 5.2.4. The information provided will be assessed to determine if a reasonable person would be satisfied with the evidence presented.

- 5.2.5. Factors which may be considered in assessing the information include:
- (a) Is the evidence of the person's view as opposed to the family's view?
 - (b) Is there corroborating evidence?
 - (c) How recent is the evidence?
 - (d) How well does the person providing the evidence know the person?

6. Deemed Consent

When there is no record of a person's decision on organ and tissue donation their consent will be considered, under law, to have been given.

- 6.1. In the absence of express consent, transplantation activities are lawful if carried out by deemed consent unless one of the following exceptions applies:
1. **Children** – deemed consent will not apply to persons under the age of majority (19). (*Section 14* of the Act).
 2. **Not Ordinarily Resident in Nova Scotia** – deemed consent will not apply to persons not ordinarily resident in Nova Scotia for 12 months immediately prior to dying. (*Section 13* of the Act).
 3. **Lack of Capacity** – deemed consent will not apply to a person who does not have the capacity to make a decision respecting donation after death for a significant period before dying. (*Section 12* of the Act).
- 6.2. If a person is not within an excluded category above, then consent may be deemed unless:
- (i) the person recorded a decision about donation in the Registry (express consent or opt out), or
 - (ii) a substitute decision maker provides information that would lead a reasonable person to conclude that the person would have objected to consent being deemed (refusal).

7. Establishing Whether Deemed Consent Applies (Exceptions)

7.1 Children

- 7.1.1. Deemed consent does not apply to persons under the age of majority. The age of majority in Nova Scotia is 19.
- 7.1.2. Deemed consent may apply to a person from 00:00 on the day of their 19th birthday.
- 7.1.3. As a general principle, if it is not possible to establish that a person is age 19 or older, the express consent process should be followed.
- 7.1.4. For persons under the age of 19, donation is still possible but it must be by express consent. A child may provide express consent if they have the capacity to make a decision respecting donation after death. Persons aged 16 and up can provide their express consent through the NS Health Card processes described in Section 4.5 of this guide. Otherwise, a substitute decision maker may provide express consent on their behalf.

7.2 Ordinarily Resident

- 7.2.1. For deemed consent to apply, a person must have lived in Nova Scotia for 12 consecutive calendar months immediately prior to their death.
- 7.2.2. As a general principle, if it is unknown or uncertain whether the person has lived in Nova Scotia for 12 calendar months, deemed consent should not apply and the express consent process should be followed.
- 7.2.3. If a person has lived in Nova Scotia less than 12 months, deemed consent does not apply and the express consent process should be followed.
- 7.2.4. If a person has lived in Nova Scotia for 12 months or longer, then it must be determined that they were ordinarily resident in Nova Scotia for deemed consent to apply.
- 7.2.5. Determining whether a person is ordinarily resident in Nova Scotia requires looking at the nature of their residency. This will be assessed on a case by case basis.
- 7.2.6. What will be considered when assessing the nature of a person's residency in Nova Scotia includes whether their residency was both voluntary and supported by the regular order of their life for the time being. A person's residency status will be assessed at the time of their death by the donation program.

- 7.2.7. As a general principle, if there is doubt about whether the person was ordinarily resident in Nova Scotia for the 12 months prior to their death, the express consent process should be followed.
- 7.2.8. Examples of certain types of residency to which deemed consent will generally NOT apply include:
- (1) Students studying in Nova Scotia who come from out of province
 - (2) International students
 - (3) Persons who come from out of province to work in Nova Scotia on a temporary basis (including foreign temporary workers)
 - (4) Persons incarcerated in Nova Scotia
 - (5) Armed Forces members posted to Nova Scotia and their families
 - (6) RCMP members posted to Nova Scotia and their families
- 7.2.9. If a person falls into a category above and deemed consent does not apply, they may still be a donor. The express consent process will be followed.

7.3 Mental Capacity

- 7.3.1. Capacity is defined in *Section 2(b)* of the Act. “Capacity” means the ability to understand the information that is relevant to a decision to be made and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.
- 7.3.2. Deemed consent does not apply to a person who, for a significant period before dying, lacked the capacity to understand that consent to transplantation activities can be deemed.
- 7.3.3. If a person is found to have lacked capacity, then the express consent process will be followed.
- 7.3.4. If, at the point a person lost capacity, deemed consent did not apply (for example they were a child or did not live in Nova Scotia) then consent cannot be deemed.
- 7.3.5. What is a significant period?
- 7.3.5.1. The exact duration is not specified in the Act.
 - 7.3.5.2. The period must be significant.
 - 7.3.5.3. Significant means a sufficiently long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed.

7.3.5.4. It will be assessed on a case by case basis.

7.3.5.5. This requirement only impacts deemed consent.
An express decision to consent or refuse remains
in effect after a loss of capacity.

8 Role of Family

8.1. Persons who qualify as substitute decision makers, in order of priority and in accordance with *Section 6(1)* of the Act, are:

- (a) a person authorized to give consent under the *Medical Consent Act* or the *Personal Directives Act*, unless the authorization excludes decisions about organ or tissue donation and, where there is more than one delegate authorized pursuant to the *Personal Directives Act*, the delegate authorized to make health-care decisions;
- (b) a guardian or representative under the *Adult Capacity and Decision-making Act* with the appropriate authority to deal with organ and tissue donation decisions;
- (c) a spouse;
- (d) a child who has reached the age of majority;
- (e) a parent;
- (f) a person standing in *loco parentis*;
- (g) a sibling;
- (h) a grandparent;
- (i) a grandchild;
- (j) an aunt or uncle;
- (k) a niece or nephew;
- (l) another relative; or
- (m) the person lawfully in possession of the individual's body.

8.2 If a person has not recorded a decision about donation in the Registry and deemed consent does not apply because an exception in *Section 7* of this guide applies to them, a substitute decision maker may give express consent or refuse consent to donation after death on behalf of the person.

8.2.1. A substitute decision maker will be asked about what information they have about the person's own wishes and will be expected to give or refuse consent on the basis of those wishes.

8.3 If a person has recorded a decision in the Registry, or deemed consent applies, and the substitute decision maker provides information that the person would have made a different decision, and the evidence provided is assessed as being sufficient to satisfy a reasonable person (see Section 5.2 above for guidance), the substitute decision maker may consent or refuse to consent on behalf of the person in accordance with that information.

8.4. Medical/Social Background

8.4.1. Family may be asked to provide medical and social information about the person in order for a risk assessment to be carried out. This is not part of the consent process but rather allows for clinical decisions to be made about donation in light of all the relevant information.

8.4.2. It should be noted that there is no requirement that donation proceed if there is express consent or consent. Rather, it means that it is lawful for donation to take place. It will be a decision for the organ donation program or tissue bank as to whether there is medical suitability/ need to proceed with donation.

9 Personal Health Information and Personal Information Protection

9.1 Information collected, used, disclosed, retained and destroyed through the Registry will be managed and protected in compliance with the Nova Scotia Personal Health Information Act.

For more information on organ and tissue donation in Nova Scotia, visit www.legacyoflife.ns.ca or www.novascotia.ca/organtissuedonation or call 1-877-841-3929.