Bill 52

An Act respecting end-of-life care

Introduction

Introduced by
Madam Véronique Hivon
Minister for Social Services and Youth Protection

Québec Official Publisher
2013
EXPLANATORY NOTES

The purpose of this bill is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy and to recognize the primacy of wishes expressed freely and clearly with respect to end-of-life care.

The bill specifies rights with respect to end-of-life care, in particular by affirming the right of everyone to end-of-life care that is appropriate to their needs.

The bill sets out special rules applicable to the providers of end-of-life care, that is, institutions, palliative care hospices and private health facilities, in order to provide a framework for the organization and regulation of end-of-life care. In this respect, it specifies the special functions and powers of health and social services agencies and of the Minister of Health and Social Services.

The bill also establishes specific requirements for certain types of end-of-life care, namely terminal palliative sedation and medical aid in dying. It prescribes the criteria that must be met for a person to obtain medical aid in dying and the requirements to be complied with before a physician may administer it. It also prescribes the special functions of the council of physicians, dentists and pharmacists of the institutions with respect to end-of-life care.

A commission on end-of-life care is established under the name “Commission sur les soins de fin de vie”, as well as rules with respect to its composition and operations. The mandate of the Commission is to examine all matters relating to end-of-life care and to oversee the application of specific requirements relating to medical aid in dying.

The bill establishes an advance medical directives regime and specifies the conditions that must be met in order for such directives to have binding force.

Lastly, the bill contains the amending, transitional and final provisions necessary for the carrying out of this Act.
LEGISLATION AMENDED BY THIS BILL:

– Civil Code of Québec;
– Code of Civil Procedure (chapter C-25);
– Medical Act (chapter M-9);
– Act respecting health services and social services (chapter S-4.2).
Bill 52

AN ACT RESPECTING END-OF-LIFE CARE

THE PARLIAMENT OF QUÉBEC ENACTS AS FOLLOWS:

TITLE I
PURPOSE OF ACT

1. The purpose of this Act is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy. The Act establishes the rights of such patients as well as the organization of and a framework for end-of-life care so that everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering.

In addition, the Act recognizes the primacy of freely and clearly expressed wishes with respect to care, in particular by establishing an advance medical directives regime.

TITLE II
END-OF-LIFE CARE

CHAPTER I
GENERAL PROVISIONS

2. The provision of end-of-life care is to be guided by the following principles:

   (1) respect for end-of-life patients and recognition of their rights and freedoms must inspire every act performed in their regard;

   (2) end-of-life patients must be treated, at all times, with understanding, compassion, courtesy and fairness, and with respect for their dignity, autonomy, needs and safety; and

   (3) the healthcare team providing care to end-of-life patients must establish and maintain open and transparent communication with them.

3. For the purposes of this Act,
(1) “institution” means any institution governed by the Act respecting health services and social services (chapter S-4.2) that operates a local community service centre, a hospital centre or a residential and long-term care centre, as well as the Cree Board of Health and Social Services of James Bay established under the Act respecting health services and social services for Cree Native persons (chapter S-5);

(2) “palliative care hospice” means a community organization that holds an accreditation granted by the Minister under the second paragraph of section 457 of the Act respecting health services and social services and has entered into an agreement with an institution under section 108.3 of that Act in order to secure all or some of the care required by its end-of-life patients;

(3) “end-of-life care” means palliative care provided to persons at the end of their lives, including terminal palliative sedation, and medical aid in dying.

CHAPTER II
RIGHTS WITH RESPECT TO END-OF-LIFE CARE

4. This chapter complements the provisions of the Civil Code with respect to care and the provisions of the Act respecting health services and social services and of the Act respecting health services and social services for Cree Native persons with respect to the rights of users and beneficiaries.

5. Every person whose condition requires it has the right to receive end-of-life care, subject to the specific requirements established by this Act.

Such care may be provided to the person in a facility maintained by an institution, in a palliative care hospice or at home.

This section applies within the framework of the legislative and regulatory provisions relating to the organizational and operational structure of institutions and the policy directions, policies and approaches of palliative care hospices and within the limits of the human, material and financial resources at their disposal.

6. Except as otherwise provided by law, a person of full age who is capable of consenting to care may, at any time, refuse to receive, or withdraw consent to, a life-sustaining treatment or procedure; the refusal or withdrawal may be expressed by any means.

The physician must ensure that such a decision is made freely and provide the person with all information needed to make an informed decision, in particular information about other therapeutic possibilities, including palliative care.
7. A person may not be denied end-of-life care for previously having refused to receive a treatment or procedure or having withdrawn consent to a treatment or procedure.

CHAPTER III
ORGANIZATION OF END-OF-LIFE CARE

DIVISION I
SPECIAL RULES APPLICABLE TO PROVIDERS OF END-OF-LIFE CARE

§1. — Institutions

8. Every institution must offer end-of-life care and ensure that it is provided to the persons requiring it in continuity and complementarity with any other care that is or has been provided to them.

For this purpose, an institution must, among other things, establish measures to promote multidisciplinary cooperation among the different health or social services professionals practising within the institution.

9. Every institution must include a clinical program for end-of-life care in its organization plan. In the case of a local authority referred to in section 99.4 of the Act respecting health services and social services, the plan must also include in-home care for end-of-life patients.

10. Every institution must adopt a policy with respect to end-of-life care. The policy must be consistent with ministerial policy directions and be made known to the personnel of the institution, to the health and social services professionals who practise in the institution, and to end-of-life patients and their close relations.

The executive director of the institution must report annually to the board of directors on the implementation of the policy. The report must state the number of end-of-life patients who received palliative care, the number of terminal palliative sedations administered, the number of requests for medical aid in dying, the number of times such aid was administered and the number of times such requests were refused, including the reasons for the refusals.

The report must also state, where applicable, the number of terminal palliative sedations administered and the number of times medical aid in dying was administered in the premises of a palliative care hospice under agreement with the institution as well as the number of times such aid was administered by a physician practising in a private health facility with which the institution is associated in accordance with section 17.
The institution must include a summary of the report in a separate section of its annual management report.

11. Every institution must include, in the code of ethics adopted under section 233 of the Act respecting health services and social services, a section pertaining specifically to the rights of end-of-life patients.

12. When an end-of-life patient requests in-home palliative care from an institution, but the person’s condition or environment is such that proper care could not be provided at home, the institution must offer to admit the person to its facilities or direct them to another institution or to a palliative care hospice that can meet their needs.

13. An institution must offer a private room to every patient who is receiving end-of-life care in its facilities and whose death is imminent.

§2. — Palliative care hospices

14. End-of-life care may be offered in the premises of a palliative care hospice.

Every palliative care hospice must inform persons of the end-of-life care it offers before admitting them.

15. A palliative care hospice and an institution must specify in their agreement under section 108.3 of the Act respecting health services and social services the nature of the services the institution is to provide in the premises of the hospice and the monitoring mechanisms that will allow the institution, or one of its boards, councils or committees determined in the agreement, to ensure that quality care is provided in the hospice.

On the request of the institution, the palliative care hospice must communicate any information required for the carrying out of the agreement. The manner in which such information is to be communicated is specified in the agreement.

16. Every palliative care hospice must adopt a code of ethics with respect to the rights of end-of-life patients and adopt a policy with respect to end-of-life care.

These documents must be made known to the personnel of the palliative care hospice, to the health and social services professionals who practise in the hospice, and to end-of-life patients and their close relations.

§3. — Private health facilities

17. End-of-life care may be provided at the patient’s home by physicians and, within the scope of their practice, nurses who practise in a private health facility within the meaning of section 95 of the Act respecting health services and social services.
However, such a physician may not provide terminal palliative sedation or medical aid in dying otherwise than in association with the local authority of the territory where the facility is situated.

The terms of the association must be set out in a written agreement. The agreement must include the monitoring mechanisms that will allow the local authority, or one of its boards, councils or committees determined in the agreement, to ensure that quality care is provided.

On the request of the local authority, the physician must communicate any information required for the carrying out of the agreement. The manner in which such information is to be communicated is specified in the agreement.

DIVISION II
SPECIAL FUNCTIONS OF HEALTH AND SOCIAL SERVICES AGENCIES

18. Every health and social services agency must determine the general rules governing access to the end-of-life care provided by the institutions and palliative care hospices in its territory.

19. Every agency must inform the population living in its territory of the end-of-life care services available and the manner of accessing them, as well as the rights and options of end-of-life patients.

This information must be available on the websites of the agencies.

DIVISION III
SPECIAL FUNCTIONS AND POWERS OF THE MINISTER

20. The Minister determines the policy directions that are to guide institutions and agencies when organizing end-of-life care, including those institutions must take into account when formulating their end-of-life care policy.

21. The Minister may require of institutions and agencies that they supply, in the manner and within the time specified, statements, statistical data, reports and other information required for the performance of the Minister’s functions, provided it is not possible to link that information to any specific patient having received end-of-life care.

22. In order to ascertain compliance with this Title, a person authorized in writing by the Minister to carry out an inspection may, at any reasonable time, enter any premises operated by an institution or a palliative care hospice.

The person may, during an inspection,
(1) examine and make a copy of any document relating to the end-of-life care offered in those premises; and

(2) demand any information relating to the carrying out of this Title as well as the production of any related document.

Any person having custody, possession or control of such documents must make them available on request to the person conducting the inspection.

A person conducting an inspection must, if so required, produce a certificate of capacity.

Any person who hinders a person in the conduct of an inspection, refuses to provide any information or document the latter is entitled to require or examine, or conceals or destroys any document or other object relevant to an inspection is guilty of an offence and is liable to a fine of $2,500 to $25,000 in the case of a natural person and to a fine of $7,500 to $75,000 in any other case.

23. The Minister may delegate the powers provided for in section 22 to a health and social services agency.

24. A person authorized in writing by the Minister or, where applicable, by an agency to carry out an inspection may not be prosecuted for an omission or an act done in good faith in the performance of their duties.

CHAPTER IV
SPECIAL REQUIREMENTS FOR CERTAIN END-OF-LIFE CARE

DIVISION I
TERMINAL PALLIATIVE SEDATION

25. Before giving consent to terminal palliative sedation, a patient who wishes to receive such sedation or, where applicable, the individual authorized to consent to care on behalf of the patient, must among other things be informed of the prognosis, the irreversible and terminal nature of the sedation and the anticipated duration of the sedation.

Consent to terminal palliative sedation must be in writing and filed in the patient’s record.

DIVISION II
MEDICAL AID IN DYING

26. Only a patient who meets the following criteria may obtain medical aid in dying:
(1) be of full age, be capable of giving consent to care and be an insured person within the meaning of the Health Insurance Act (chapter A-29);

(2) suffer from an incurable serious illness;

(3) suffer from an advanced state of irreversible decline in capability; and

(4) suffer from constant and unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable.

The patient must request medical aid in dying themselves, in a free and informed manner, by means of the form prescribed by the Minister. The form must be dated and signed by the patient or, if the patient is physically incapable of doing so, by a third person. The third person may not be a minor or an incapable person of full age or a member of the team responsible for caring for the patient.

The form must be signed in the presence of a health or social services professional who countersigns it; if the professional countersigning is not the attending physician, the signed form is given to the attending physician.

27. A patient may, at any time and by any means, withdraw their request for medical aid in dying.

28. Before administering medical aid in dying, the physician must

(1) be of the opinion that the patient meets the criteria of section 26, after, among other things,

(a) making sure that the request is being made freely and without any external pressure;

(b) making sure that the request is an informed one, in particular by informing the patient of the prognostic and of other therapeutic possibilities and their consequences;

(c) verifying the persistence of suffering and that the wish to obtain medical aid in dying remains unchanged, by talking to the patient at reasonably spaced intervals given progress of the patient’s condition;

(d) discussing the patient’s request with any members of the care team who are in regular contact with the patient; and

(e) discussing the patient’s request with the patient’s close relations, if the patient so wishes;

(2) make sure that the patient has had the opportunity to discuss the request with the persons they wished to contact; and
(3) obtain the opinion of a second physician confirming that the criteria set out in section 26 have been met.

The physician consulted must be independent of both the patient requesting medical aid in dying and the physician seeking the second medical opinion. The physician consulted must consult the patient’s record, examine the patient and provide the opinion in writing.

29. If a physician determines, subsequent to the application of section 28, that medical aid in dying may be administered to a patient requesting it, the physician must administer such aid personally and take care of the patient until their death.

If the physician determines that medical aid in dying cannot be administered, the physician must inform the patient of the reasons for that decision.

30. A physician practising in a centre operated by an institution who refuses a request for medical aid in dying for a reason not based on section 28 must as soon as possible notify the director of professional services or any other person designated by the executive director of the institution and forward the request form given to the physician, if such is the case, to the director of professional services or designated person. The director of professional services or designated person must then take the necessary steps to find another physician willing to deal with the request in accordance with section 28.

If the physician who receives the request practises in a private health facility and is not associated with a local authority for the administration of medical aid in dying, the physician must as soon as possible notify the director of professional services or any other person designated by the executive director of the local authority, and forward the request form given to the physician, if such is the case, to the director of professional services or designated person. The steps mentioned in the first paragraph must then be taken.

31. All information and documents in connection with a request for medical aid in dying, regardless of whether the physician administers it or not, including the form used to request such aid, the reasons for the physician’s decision and, where applicable, the opinion of the physician consulted, must be recorded or filed in the patient’s record.

DIVISION III
SPECIAL FUNCTIONS OF THE COUNCIL OF PHYSICIANS, DENTISTS AND PHARMACISTS

32. The council of physicians, dentists and pharmacists established for an institution must, in accordance with the clinical standards established by the professional orders concerned, adopt clinical protocols applicable to terminal palliative sedation and medical aid in dying.
33. A physician who provides terminal palliative sedation or medical aid in dying must, once it is administered, give notice to the council of physicians, dentists and pharmacists of which the physician is a member, whether it is administered in the facilities of an institution, in the premises of a palliative care hospice or at the patient’s home; if the physician practises in a private health facility, the notice is to be given to the council of physicians, dentists and pharmacists established for the local authority with which the physician is associated.

The council of physicians, dentists and pharmacists or its competent committee assesses the quality of the care provided, particularly with regard to applicable clinical protocols.

34. If no council of physicians, dentists and pharmacists is established for the institution, the head of medical services or the physician responsible for medical care in the institution, as applicable, assumes the functions assigned to the council under this division, and the notice provided for in the first paragraph of section 33 is sent to that person.

CHAPTER V
COMMISISON SUR LES SOINS DE FIN DE VIE
DIVISION I
ESTABLISHMENT AND FUNCTIONING OF THE COMMISSION

35. A commission on end-of-life care (“the Commission”) is established under the name “Commission sur les soins de fin de vie”.

36. The Commission is composed of seven members, appointed by the Government as follows:

(1) four members are to be health or social services professionals, including at least two physicians, appointed after consultation with the professional orders concerned;

(2) one member is to be a jurist, appointed after consultation with the professional orders concerned;

(3) one member is to be a user of an institution, appointed after consultation with bodies representing the users’ committees of the institutions; and

(4) one member is to be from the ethics community, appointed after consultation with university-level teaching institutions.

The members of the Commission are appointed for a term of not more than five years. Their terms of office may be renewed consecutively only once. At the expiry of their terms, members remain in office until they are replaced or re-appointed.
The Government designates, from among the members of the Commission, a chair and vice-chair; the vice-chair shall chair the Commission when the chair is absent or unable to act.

The Government fixes the allowances and indemnities of the members of the Commission.

37. The Commission may make by-laws concerning its internal management.

38. The quorum at meetings of the Commission is five members, including the chair or the vice-chair.

Subject to the second paragraph of section 42, the decisions of the Commission are made by a majority vote of the members present. In the case of a tie vote, the person presiding at the meeting has a casting vote.

DIVISION II
MANDATE OF THE COMMISSION

39. The mandate of the Commission is to examine any matter relating to end-of-life care. For this purpose, it must, among other things,

(1) advise the Minister on any matter put before it by the Minister;

(2) evaluate the implementation of legislation with regard to end-of-life care;

(3) refer to the Minister any matter relating to end-of-life care that needs the attention of or action by the Government, and submit its recommendations to the Minister;

(4) submit a report to the Minister, every five years, on the status of end-of-life care in Québec; and

(5) carry out any other mandate given to it by the Minister.

The Commission also has the mandate of overseeing the application of the specific requirements relating to medical aid in dying in compliance with this division.

The Commission submits an annual activity report to the Minister.

40. In exercising its functions under the first paragraph of section 39, the Commission may

(1) solicit opinions on any matter concerning end-of-life care from individuals or groups;
(2) conduct or commission studies and research it deems necessary; and

(3) call on outside experts to report to it on one or more specific points.

41. A physician who administers medical aid in dying must give notice to the Commission within the next 10 days and send the Commission, in the manner determined by government regulation, the information prescribed by regulation. This information is confidential and may not be disclosed to any other person, except to the extent that is necessary for the purposes of this section and section 42.

A physician who contravenes this section is guilty of an offence and is liable to a fine of $1,000 to $10,000.

42. On receiving the notice from the physician, the Commission assesses compliance with section 28 in accordance with the procedure prescribed by government regulation.

On completion of the assessment, if two-thirds or more of the members present are of the opinion that section 28 was not complied with, the Commission sends a summary of its conclusions to the physician, to the institution concerned, to the Collège des médecins du Québec and to any other authority concerned.

CHAPTER VI
MISCELLANEOUS PROVISIONS

43. A person’s decision to refuse to receive a treatment or procedure, to withdraw consent to a life-sustaining treatment or procedure or to request terminal palliative sedation or medical aid in dying may not be invoked as a reason to refuse to pay a benefit or any other sum due under a contract.

44. This Act does not limit the right of health professionals to refuse, in accordance with their code of ethics, to provide or take part in providing end-of-life care for reasons of conscience.

TITLE III
ADVANCE MEDICAL DIRECTIVES

CHAPTER I
GENERAL PROVISIONS

45. A person of full age who is capable of giving consent to care may specify, in advance medical directives, what care required by their state of health they consent or do not consent to, in the event that they become incapable of giving consent.
In addition to instructions relating to care, the directives may include the names of one or more trusted persons who are to give them, at the appropriate time, to the attending physician or to another health professional providing care to the person.

46. Advance medical directives are given by notarial act en minute or in the presence of witnesses on the form prescribed by the Minister.

47. Directives given in the presence of witnesses must be written by the person themselves or, if the person is physically incapacitated, by a third person in accordance with the person’s instructions.

In the presence of two witnesses, the person declares that the document is the person’s advance medical directives, but need not disclose the contents. The person dates and signs the directives at the end or, if this is already done, recognizes the signature as their own; also, if the person is physically incapacitated, the directives may be signed by a third person in the person’s presence. The directives are then signed by the witnesses in the presence of the person and of the third person, where applicable.

An incapable person of full age or a minor may not act as a third person or a witness for the purposes of this section.

48. Advance medical directives may be revoked at any time and by any means by the person concerned.

Such directives may only be changed by writing new ones by one of the methods specified in section 46. The new directives replace any previous ones.

49. When advance medical directives are given to a health professional, that professional records them in the advance medical directives register established under section 57 and files them in the record of the person concerned. If the directives are given to the health professional by the person concerned and the person is capable of giving consent to care, the health professional must first inquire whether they still correspond to the person’s wishes.

50. A physician who notes a significant change in the condition of a person capable of giving consent to care must, if advance medical directives have been filed in the person’s record, inquire whether the directives still correspond to the person’s wishes.

51. A physician who notes that a person is incapable of giving consent to care consults the advance medical directives register. If the register contains advance medical directives for the person, the physician files them in the person’s record.

52. When a person is incapable of giving consent to care, clearly expressed instructions relating to care that are recorded in the advance medical directives
register or filed in the person’s record carry, for all health professionals having access to the register or record, the same weight as wishes expressed by a person capable of giving consent to care.

53. The author of advance medical directives is presumed to have been in the possession of the information needed to make an informed decision at the time of signing the directives.

54. If a person incapable of giving consent to care categorically refuses care which they had previously consented to in advance medical directives, article 16 of the Civil Code, requiring the authorization of the court, applies.

55. The court may, on the application of the mandatory, tutor, curator of or any person showing a special interest in the author of advance medical directives, order that the instructions relating to care expressed in those directives be carried out.

The court may also, on the application of such a person, invalidate advance medical directives, in full or in part, if it has reasonable grounds to believe that the author of the directives was not capable of consenting to the care at the time of signing the directives or that the directives do not correspond to the author’s wishes in the present situation.

The court may, in addition, make any other order it considers appropriate in the circumstances.

56. Instructions relating to care expressed in a mandate given in anticipation of a person’s incapacity do not constitute advance medical directives within the meaning of this Act and remain subject to articles 2166 and following of the Civil Code.

In case of inconsistency between those instructions for care and the instructions contained in advance medical directives, the latter prevail.

CHAPTER II
ADVANCE MEDICAL DIRECTIVES REGISTER

57. The Minister establishes and maintains an advance medical directives register.

The Minister may manage the register or entrust its management to a body that is subject to the Act respecting Access to documents held by public bodies and the Protection of personal information (chapter A-2.1). In the latter case, the Minister enters into a written agreement with the manager.

58. The Minister prescribes, by regulation, how the register is to be accessed and operated, including who may record advance medical directives in the register, in addition to what is provided in section 49, and who may consult it.
TITLE IV
AMENDING, TRANSITIONAL AND FINAL PROVISIONS

CHAPTER I
AMENDING PROVISIONS

CIVIL CODE OF QUÉBEC

59. Article 11 of the Civil Code of Québec is amended

(1) by adding the following sentence at the end of the first paragraph: “Except as otherwise provided by law, the consent is subject to no other formal requirement and may be withdrawn at any time, even verbally.”;

(2) by inserting “and has not drawn up advance medical directives under the Act respecting end-of-life care (insert the year and chapter number of this Act) by which he expresses such consent or refusal” after “care” in the second paragraph.

60. Article 12 of the Code is amended by replacing “taking into account, as far as possible, any” in the first paragraph by “complying, as far as possible, with any”.

61. Article 15 of the Code is amended by inserting “and in the absence of advance medical directives” after “state of health”.

CODE OF CIVIL PROCEDURE

62. Article 776 of the Code of Civil Procedure (chapter C-25) is amended by adding the following sentence at the end of the first paragraph: “The same applies to any application under section 55 of the Act respecting end-of-life care (insert the year and chapter number of this Act) concerning the carrying out of advance medical directives.”

MEDICAL ACT

63. Section 31 of the Medical Act (chapter M-9) is amended

(1) by replacing the first paragraph by the following paragraph:

“31. The practice of medicine consists in assessing and diagnosing any health deficiency in a person in interaction with their environment, in preventing and treating illness to maintain or restore health or to provide appropriate symptom relief.”;

(2) by adding the following subparagraph at the end of the second paragraph:
“(12) administering the drug or substance allowing an end-of-life patient to obtain medical aid in dying under the Act respecting end-of-life care (insert the year and chapter number of this Act).”

ACT RESPECTING HEALTH SERVICES AND SOCIAL SERVICES

64. Section 19 of the Act respecting health services and social services (chapter S-4.2), amended by section 160 of chapter 23 of the statutes of 2012, is again amended by adding the following subparagraph after subparagraph 13:

“(14) in a case where the information is communicated for the purposes of the Act respecting end-of-life care (insert the year and chapter number of this Act).”

CHAPTER II
TRANSITIONAL AND FINAL PROVISIONS

65. Despite section 8, an institution which, on (insert the date of coming into force of section 8), operates a general and specialized hospital centre and, within the range of care that may be offered pursuant to the mission of such a centre, only offers palliative care may continue to offer that care exclusively.

Such an institution must inform persons of the end-of-life care it offers before admitting them.

66. Until (insert the date occurring two years after the date of coming into force of section 10), executive directors of institutions must report every three months to their board of directors as described in the second paragraph of section 10.

67. Institutions and palliative care hospices have until (insert the date occurring one year after the date of coming into force of section 15) to amend the agreement they have entered into under section 108.3 of the Act respecting health services and social services (chapter S-4.2) in order to bring it into conformity with section 15.

68. The Minister must, not later than (insert the date occurring five years after the date of coming into force of this section) and subsequently every five years, report to the Government on the carrying out of this Act.

Such report is tabled by the Minister in the National Assembly within the next 30 days or, if the Assembly is not sitting, within 30 days of resumption. The report is examined by the competent committee of the National Assembly.

69. The Minister of Health and Social Services is responsible for the administration of this Act.
70. The provisions of this Act come into force on the date or dates to be set by the Government.