

MEDICAL ASSISTANCE IN DYING: WHERE DO WE STAND?

CONFERENCE ORGANISED BY THE **AMYTROPIC LATERAL SCLEROSIS SOCIETY OF QUEBEC**

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REPORTING FRAME

1. PERSPECTIVE
2. LEGAL BASIS
3. HISTORICAL SUMMARY
4. LEGISLATIVES CHANGES
5. CHALLENGES AHEAD
6. CONCLUSION

PERSPECTIVE

- SERIOUS QUESTION RAISING DEBATES
- END-OF-LIFE CONCERNS EVERYONE
- LEGAL DEVELOPMENTS
- EXPRESSED WISHES' RESPECT

BASIS: FUNDAMENTAL RIGHTS

EVERY HUMAN BEING HAS A RIGHT TO

- LIFE
- FREEDOM
- SAFEGUARD OF DIGNITY



art. 1 et 4 of the *Charter of Human rights and freedoms*

DIGNITY + EQUALITY

- THE *CHARTER OF HUMAN RIGHTS AND FREEDOMS* STATES IN ITS PREAMBLE THAT the notion of dignity is an underlying value of the rights and freedoms guaranteed in the Charter:

“Whereas all human beings are equal in worth and dignity, and are entitled to equal protection of the law”

DIGNITY + FREEDOM

“The idea of **human dignity** finds expression in almost every right and freedom guaranteed in the Charter. Individuals are afforded the **right to choose** their own religion and **their own philosophy of life**, the right to choose with whom they will associate and how they will express themselves, the right to choose where they will live and what occupation they will pursue.

These are all examples of the basic theory underlying the Charter, namely that the state will respect **choices made by individuals** and, to the greatest extent possible, will avoid subordinating these choices to any one conception of the good life.”

R. vs Morgentaler , SCC 1988

AUTONOMY

A PERSON, WHATEVER HIS OR HER AGE, HAS THE RIGHT THAT BE RESPECTED IN THE EXERCISE OF HIS OR HER AUTONOMY, INDEPENDANCE AND WISHES.

SC Judge Hélène Lebel, 2006

HISTORICAL SUMMARY

1892 – Criminal Code prohibits MAID (sect. 241)

1992 – Nancy B., SC Judge Dufour

« Ce que demande Nancy B., invoquant le principe de l'autonomie de sa volonté, son droit à l'autodétermination, c'est que l'on cesse de lui appliquer le traitement de soutien respiratoire pour que la nature suive son cours, c'est qu'on la libère de l'esclavage d'une machine, sa vie dût-elle en dépendre. Pour que cela soit fait, incapable de le réaliser elle-même, il faut l'aide d'un tiers. Là et alors, c'est la maladie qui suivra son cours naturel. » (1992) RJQ 365.

HISTORICAL SUMMARY

- When the continuation of treatment is useless, it is appropriate to ask discontinuation of treatment.
- Courts have sentenced physicians who caused their patients' death to end their suffering.

HISTORICAL SUMMARY

- 1983 – Law Reform Commission on euthanasia (Reflexion document)
- 1991 – Federal bill (Axworthy): euthanasia certificate (Netherlands)
- 1993 – SCC – S. Rodriguez (5:4):
 - Physician-assisted suicide is an indictable offence
 - S. 241 Crim. Code not contrary to the Canadian Charter
 - Slippery slope (majority)
 - Medical reality (minority)

HISTORICAL SUMMARY

- 1994 – Federal bill (S. Robinson) :
decriminalization of medically assisted suicide
- 2002 – European Court (D. Pretty) : no right to
physician-assisted suicide
- 2005 – Federal bill (F. Lalonde): extend the right
to assisted death to any person, for ending a
debilitating illness and allow dying in dignity with
the person's free and enlightened consent

HISTORICAL SUMMARY

- 2007 – Canadian medical Association
 - Physicians may not participate in medically-assisted death nor assisted suicide
 - All Canadians should have access to palliative care

- 2009 – Collège des médecins du Québec
 - Statement regarding the existence of a social debate not exclusive to physicians

HISTORICAL SUMMARY

- 2009 – Commission on legal and ethical issues regarding end-of-life
- 2012 – Report of the Special commission on the right to die in dignity
- 2013 – Bill 52 : end-of-life care (June)
- 2014 – Bill unanimously adopted (June)
- 2015 – Act coming into force (December)

HISTORICAL SUMMARY

- 2011 – Synthesis document (Parliament Library)
- 2012 – Judge Smith from B.C. – Carter : s. 241b) Crim. Code contravenes s. 7 of the Canadian Charter
- 2015 – SCC : **Carter** – unanimous (February)
 - Sections 14 and 241b) are unconstitutional as they refrain physicians to provide medical assistance in dying to a person capable to consent, making such a demand and suffering from an irremediable condition causing intolerable and irremediable suffering
 - Delay of one year to modify the law

HISTORICAL SUMMARY

- 2016 – Bill C-14 : requirements (s. 241.1 and 242.2 Cr.C.)
 - Eligible for publicly funded health care services in Canada
 - 18 years of age and capable of making decisions with respect to their health
 - Have a grievous and irremediable medical condition:
 - Have a serious and incurable illness, disease or disability
 - In an advanced state of irreversible decline in capability
 - Enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable
 - ~~Their natural death has become reasonably foreseeable~~
 - Informed consent (free and clear)

HISTORICAL SUMMARY

- Federal et provincial laws are similar, but come in contradiction at times and create a complex situation around the patient.
- 2016 : professional corporations in Quebec joined and prepared a report proposing standards to follow when providing MAID:
 - The act is never trivial
 - Professionals must provide the most appropriate care to their patients. They have no duty to provide MAID
 - When providing MAID, physicians must act with respect, tact and compassion.

RECENT HISTORY

- 2019: REPORT OF PROFESSIONAL EXPERTS (13) regarding the question of incapacity and MAID (14 recommendations):
 - Right to MAID is preserved if incapacity has occurred between time of acceptance of the demand and of the moment of administration.
 - Advanced requests of MAID in view of incapacity may be accepted, pending certain conditions.
 - Advanced requests of MAID after issuance of a serious and incurable illness, be recognized.

RECENT HISTORY

- The case of Truchon and Gladu - 2019 – SC judge C. Baudouin (760 par.) (September) :
 - The standards of “end of life” (QC) and “natural death reasonably foreseeable” (Can) are unconstitutional
 - Delay of 6 months to modify the laws

RECENT HISTORY

- In Québec, the criteria of “foreseeable death” in the Act adopted in 2014 does not apply since March 12, 2020
- In Canada, the delay to modify the *Criminal Code* was reported from March 12, to July 11, to December 18, 2020 (pandemy) and finally to February 26, 2021.

MEDICAL AID IN DYING - REQUIREMENTS

1. BE **FULL OF AGE**
2. BE AN INSURED PERSON WITHIN THE MEANING OF THE HEALTH INSURANCE ACT
3. BE **CAPABLE** OF GIVING CONSENT TO CARE
4. SUFFER FROM A SERIOUS AND INCURABLE **ILLNESS**
- ~~5. BE AT THE END OF LIFE~~
6. BE IN AN ADVANCED STATE OF **IRREVERSIBLE** DECLINE IN CAPABILITY
7. EXPERIENCE CONSTANT AND UNBEARABLE PHYSICAL OR PSYCHOLOGICAL **SUFFERING** WHICH CANNOT BE RELIEVED IN A MANNER THE PATIENT DEEMS TOLERABLE (SEDATION, PALLIATIVE CARE, ETC.)

LEGISLATIVES CHANGES: BILL C-7 – MARCH 17, 2021

- Standard of “natural death reasonably foreseeable” is **abrogated** to be eligible to MAID
- Not permitted when **mental health** is the sole medical condition (expert report due March, 17, 2022)
- Permitted when a person eligible for whom natural death is reasonably foreseeable and has lost, before the act, **capacity to consent** to MAID, if he/she has concluded a previous agreement with the medical or nurse practitioner (waiver of final consent)
- Permitted to a person who has lost **capacity to consent**, after receiving a substance within the realm of care regarding MAID in view of provoking the death.

CONSULTATION - QUÉBEC SPECIAL COMMISSION ON AMENDING THE EXISTING LAW: MARCH – AUGUST 2021

- Permit access to persons with **mental health illness**
- Permit renunciation to final consent final (when incapacity occurs between request and application of MAID)
- Permit advanced request further to diagnosis of grave and incurable disease, **in case of incapacity**
- Permit advanced request for persons when mental health trouble is the sole medical condition invoked
- Permit advanced request in view of an hypothetical condition
- Permit specialized nurse practitioners to administer MAID
- Authorize access to MAID to persons with **preexisting incapacity**
- Set up a group of experts to analyse the situation of **minors**

MEDICAL AID IN DYING (MAID) - CRITERIA

1. Be eligible for health services funded by the province
2. Be at least 18 years old and mentally competent.
3. Have a grievous and irremediable medical condition
4. Make a voluntary request for MAID that is not the result of outside pressure or influence
5. Give informed consent to receive MAID

MEDICAL AID IN DYING (MAID)

1. CANNOT BE ASKED IN ADVANCE
2. CANNOT BE CONSENTED FOR / BY SOMEONE ELSE
3. CANNOT BE INCLUDED IN ADVANCE MEDICAL DIRECTIVES
4. CONSENT TO DISCONTINUE TREATMENT IS NOT MAID
5. ONLY A DOCTOR MAY ADMINISTER MAID, IN QC

NOTION OF CONSTANT AND UNBEARABLE PHYSICAL OR PSYCHOLOGICAL SUFFERING

PHYSICAL SUFFERING AT THE END OF LIFE	PSYCHOLOGICAL SUFFERING AT THE END OF LIFE
Cachexy	Total ou quasi-total dependance
Pain	Despair facing a situation with no way out
Dysphagia	Loss of dignity
Dyspnea	
Exhaustion	
Hemorrhages	
Digestive obstruction	
Paralysis	
Important wounds	
Transfusions, punctures and other repetitive proc�edures	

END-OF-LIFE CARE



END-OF-LIFE CARE ACT - 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.

MAID – QUÉBEC - RIGHTS

- **Every person** whose condition requires it has the **right to receive** end-of-life care, subject to the specific requirements established by the law.
- Such care is provided to the person in a facility maintained by an **institution** (CLSC, Hospital, CHSLD), in a **palliative care hospice** or **at home**.
- The right to receive MAID applies within the framework of the legal 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.

MAID – STEPS FOR THE REQUEST

1. EXPRESS **CHOICE** AND DISCUSS IT WITH PHYSICIAN
2. REQUEST AND **FILL THE FORM** PRESCRIBED BY THE MINISTER
3. **DATE AND SIGN** THE FORM IN THE PRESENCE OF AND COUNTERSIGNED BY A HEALTH OR SOCIAL SERVICES PROFESSIONAL; ATTENDING PHYSICIAN MUST RECEIVE COPY OF SIGNED FORM.
4. IF THE PERSON REQUESTING MAID IS INCAPABLE TO SIGN, A THIRD PERSON MAY DO SO IN HIS / HER PRESENCE. THIS PERSON MAY NOT BE A MINOR, AN INCAPABLE ADULT OR A PROFESSIONAL OF THE TREATING TEAM

MAID – STEPS FOR THE REQUEST

5. FORM IS SIGNED BY ONE PHYSICIAN AND TWO **INDEPENDANT WITNESSES** (same conditions as above)
6. REQUEST MUST BE REPETED AT EACH MEDICAL VISIT
7. REQUEST MAY BE **RETREIVED OR POSTPONED AT ALL TIMES AND BY ANY MEANS**

MAID – STEPS – BEFORE ADMINISTERING

Physician must

1. be of the opinion that the person meets all the criteria:
 - a) request is being made freely (no external pressure);
 - b) request is informed (prognosis for the illness, other therapeutic possibilities and their consequences);
 - c) persistence of suffering and the wish to obtain medical aid in dying remains unchanged;
 - d) discuss the patient's request with any members of the care team who are in regular contact with the patient; and
 - e) discuss the patient's request with the patient's close relations, if the patient so wishes;

MAID – STEPS – BEFORE ADMINISTERING

Physician must

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 have been met

MAID - STEPS

If a physician determines that medical aid in dying **may be administered** to a patient requesting it, the physician must administer such aid personally and take care of and stay with the patient until death ensues.

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

A physician who **refuses to administer** medical aid in dying based on personal reasons must, as soon as possible, notify the executive director of the institution who must then take steps to find, as soon as possible, another physician.

MAID – TWO TYPES

1. Physician directly administers a substance that causes death, such as an injection of a drug (clinician-administered medical assistance in dying)

or

2. Physician provides or prescribes a drug that the eligible person takes by himself / herself, in order to bring about his / her own death (self-administered medical assistance in dying)

MAID - STATISTICS

1. 7 595 **cases** of MAID declared in Canada in 2020:
 - a) Representing 2,5 % of all deaths for 2020
 - b) Representing a raise of 34,2 % compared to 2019
 - c) Proportion men / women is similar (51,9% / 48,1%)
 - d) Middle age = 75,3 ans
 - e) Cancer (69,1%) is the health problem most cited
 - f) Neurological trouble represent 10,2% of all cases
 - g) More than 80% of the persons had received palliative care
 - h) Most often delivered at domicile, or hospital, by treating physician

2. 9 375 **requests** of MAID declared in Canada en 2019
 - a) 1991 have not succeeded :
 1. Death prior to administration (1 193)
 2. Inadmissibles (566; 27,7% because death was not reasonably foreseeable)
 3. Withdrawals (232)

CHALLENGES AHEAD

- ADVANCED REQUESTS (DIAGNOSIS, HYPOTHETICAL)
 - MINORS
 - SUBSTITUTE CONSENT TO CARE FOR INCAPABLE PERSONS
 - UNBEARABLE SUFFERING: EVALUATION
 - EXCLUSION FOR PERSONS WITH MENTAL ILLSNESS BEING THE ONLY MEDICAL CONDITION (March 17, 2023)
 - ADMINISTRATION BY NURSES PRACTITIONER
 - DISCREDITING THE VALUE OF LIFE (SLIPPERY SLOPE)

CONCLUSION

- RECENT EVOLUTION MORE FAVORABLE TO EXERCISE OF INDIVIDUAL RIGHTS AND WISHES
- PROTECTION AND RESPECT OF LIFE
- CONTINUING SOCIAL DEBATE

Thank you for your attention

Speaking time!

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USEFUL REFERENCES

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<http://www.ramq.gouv.qc.ca/fr/citoyens/assurance-maladie/volontes/Pages/directives-medicales-anticipees.aspx>

Coll  ge des m  decins

La s  dation palliative en fin de vie (08/2016) :

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<http://www.educaloi.qc.ca/search/node/directives%20m%C3%A9dicales%20anticip%C3%A9es>
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