AQDMD ASSOCIATION QUÉBÉCOISE POUR LE DROIT DE MOURIR DANS LA DIGNITÉ

Select Committee on the Evolution of the Act Respecting End-of-Life Care
Civic engagement survey

Background overview:

The Committee aims to study issues related to the potential expansion of medical assistance in dying (MAID) for persons who are incapacitated and for persons whose sole medical problem is a mental disorder. Citizens are invited to participate, through a questionnaire located on the National Assembly website.

Link to the questionnaire:

https://questionnaire.simplesondage.com/f/s.aspx?s=6a94e598-5c7a-48a0-b47c-0f56d0601fe0

Objective:

This document presents the AQDMD's position regarding each of the points addressed in the questionnaire. It lists the responses to questions word-for-word, except for cases in which the AQDMD does not agree or has a more nuanced position. Clarifications have sometimes been added.

THE AQDMD'S POSITION ON POINTS ADDRESSED IN THE QUESTIONNAIRE

Questions 1 to 7 are personal.

1) Medical assistance and incapable patients

Question 8: In your opinion, are there any situations in which a person who is not capable of consenting to care should be eligible for medical aid in dying?
Here is the AQDMD position on this issue:

- In some situations, it may be justifiable for a person who has become incapable of consenting to care to benefit from medical aid in dying.

Clarification: this is especially true for people affected by neurocognitive degenerative diseases. These diseases are physical illnesses that affect the patient's cognitive state, with a limited life expectancy. This is the case, for instance, with Alzheimer's disease.

Question 9: The following arguments are sometimes made about access to medical aid in dying for persons who are incapacitated.
Here is the AQDMD position concerning the arguments presented:

- The requirement that a person be capable of consent interferes with his or her right to make decisions about his or her end of life.

- It may be difficult for the care team or loved ones to accurately assess a person's suffering, but the care team has many means at its disposal to assess this.

- Allowing advance application for medical aid in dying could send a negative signal about the value society places on the lives of persons with a neurodegenerative disease.

Clarification: On the contrary, this is about respecting a person's wishes and prioritizing respect for the individual's wishes, their dignity according to their own values, and their right to avoid suffering.

- Granting an advance request for medical aid in dying to a person with a neurodegenerative disease would spare him or her an end of life that he or she considers contrary to his or her values and dignity.

Clarification: This will allow the individual to live their last years of lucidity in peace and spare them the anguish of prolonged suffering. This will also allow them to avoid considering ending their life early, in order to benefit from MAID while they are capable of consent.

Question 10: Several categories of persons who are incapacitated could, on reasonable grounds, have access to medical aid in dying.
Here is the AQDMD position concerning the situations presented:

- A person who has never been capable of consenting to healthcare, such as a person suffering from a severe intellectual disability should not be able to have access to medical assistance in dying, unless there are no doubts as to their wishes.

- A person who has been diagnosed with a neurodegenerative disease such as Alzheimer's-type dementia or another related disease and who requested it while capable should absolutely be able to have access to medical aid in dying.

- A person who has been the victim of a sudden and unexpected accident with serious and irreversible after-effects, such as a stroke, and who requested it while capable [should not have access to medical aid in dying].

> Clarification: Accepting this type of request would amount to giving advance consent to medical assistance in dying for any acute medical condition that may arise in the life of the individual because the prognosis could not be known in advance. The usual rules for avoiding therapeutic obstinacy apply in this type of case.

Question 11: In order for a person to be able to receive medical aid in dying once he or she has become incapacitated, it has been proposed that he or she should be able to make his or her wishes known in advance while still able to consent to care.
Here is the AQDMD position regarding the points presented:

- A person should be able to request medical aid in dying in advance if he or she meets all the criteria.

- In order to request medical aid in dying in advance, a person would absolutely need to have been diagnosed with a serious and incurable disease.

- Any advance request for medical aid in dying that meets the person's criteria should obligatorily be complied with.

> Clarification: The request must be enforceable and binding for the substitute decision maker and the healthcare team, even if the patient does not appear to be in a state of distress at the time MAID is to be administered.

- Medical aid in dying requested in advance should be administered even if the person does not appear to be suffering.

- The responsibility for determining whether the time has come to apply the advance request should rest with the physician or medical team.

- The responsibility for determining whether the time has come to apply the advance request should rest with a designated loved one.

Clarification: This loved one must be the substitute decision maker who was formally appointed by the applicant. They can inform the medical team that the time chosen by the patient has arrived, and the healthcare team must verify that the patient's condition complies with their request.

Question 12: If it were to become possible to make an advance request for medical aid in dying, it would be necessary to provide for the terms and conditions.
Here is the AQDMD position regarding the points presented:

- The oral request should not be admissible. It must be written.

- The request made in writing before a witness should be admissible.

- The request made by audio-visual recording should be admissible.

Clarification: The law already provides a solution for people who are not able to provide a signature.

- The request does not need to be notarized.

- The request does not need to have a defined period of validity.

- The request should be easily amendable or revocable by the person who made it.

- The request should contain detailed information about the suffering and living conditions that the person is anticipating and finds unbearable.

Question 13: Do you have any other comments on access to medical aid in dying for persons who are incapacitated? You will also have the opportunity, if you wish, to attach a document at the end of the questionnaire.
Here is the AQDMD position for this question:

Any person suffering from a neurocognitive degenerative disease should not live their last years of lucidity in fear of a painful end-of-life, nor be afraid of losing their dignity at the same time as their lucidity.

If they wish to do so and as long as they have the capacity to consent, individuals should therefore be able to choose to receive medical assistance in dying at a later date, even if they have lost cognitive function by the date upon which the decision would be applied.

The patient must determine the point past which they do not want to live, as the disease progresses and their condition deteriorates. They should therefore be able to choose the appropriate moment to benefit from MAID, before their dignity or their autonomy are affected, according to their values and with full decision-making capacity.

2) Medical assistance in dying and mental disorder

The Association's position: the term "mental disorder" refers to psychological problems that, though their future progression may be uncertain, are nonetheless real illnesses that cause real suffering that can be intolerable and treatment resistant.

Question 14: In your opinion, should medical aid in dying be available to persons whose only medical problem is a mental disorder?
Here is the AQDMD position for this question:

- Medical aid in dying should be available to people with a single mental disorder.

Question 15: The following arguments are sometimes made about access to medical aid in dying for persons whose only medical problem is a mental disorder.
Here are the AQDMD positions regarding the arguments presented:

- Some mental disorders may be incurable and cause intolerable suffering.

    Clarification: These people are suffering just as much as those with physical conditions.

- Denying medical aid in dying to people with a mental disorder would be discriminatory, as this decision would be based on a diagnosis and not on the individual's circumstances and living conditions.

    Clarification: There is no reason that people suffering from a mental disorder (when it is serious and treatment resistant) should not benefit, like other citizens, from MAID.

- A mental disorder cannot be declared with certainty to be incurable. A case that is deemed irreversible may eventually be alleviated with treatment.

    Clarification: This is why each case must be evaluated exhaustively (duration of the illness, number of attempted treatments, etc.).

- Granting medical aid in dying on the grounds of mental disorder could give the impression that death is an option for ending suffering rather than obtaining treatment.

> Clarification: Medical assistance in dying would be a solution for cases in which the disorder is treatment resistant. This is not about encouraging suicide. Instead, MAID would aim to limit suffering when medicine can no longer do so, just like with other conditions that are eligible for MAID.

- The criteria already provided for in the Act Respecting End-of-Life Care would be sufficient to regulate access to medical aid in dying for persons whose sole medical problem is a mental disorder, thus avoiding any abuse.

> Clarification: We must bring together experts and stakeholder groups to define the criteria for access to MAID, especially to distinguish between suicidal thoughts as symptoms and a wish that has been well thought out.

- There are risks of abuse if access to medical aid in dying is granted to persons with mental disorders.

> Clarification: this is why a clinical assessment, on a case-by-case basis, is essential.

Question 16: Certain conditions could be put in place to regulate access to medical aid in dying for persons whose only medical problem is a mental disorder.
Here are the AQDMD positions, point by point:

- There must be a minimum period of time between the time the diagnosis is received and the request for medical aid in dying.

- The person must have tried at least one treatment that could reasonably improve his or her situation.

- The person must have been assessed by at least one psychiatrist.

- The person must have a mental disorder that is deemed incurable.

- The person's loved ones must be involved in the process.

> Clarification: People who do not have loved ones by their side should nevertheless have access to medical assistance in dying, according to clinical criteria.

- The person must not have refused treatment that offers a reasonable possibility of alleviating his or her suffering.

> Clarification: The AQDMD deems this to be a matter of human rights and one that relates to the Charters.

- The person must have had prior access to care and services aimed at improving his or her condition.

Question 17: Do you have any other comments on access to medical aid in dying for people whose only medical problem is a mental disorder? You will also have the opportunity, if you wish, to attach a document at the end of the questionnaire.

Medical assistance in dying may be an option for the patient when the mental disorder is treatment resistant. This is not about promoting suicide. Instead, it would aim to reduce suffering when medicine can no longer do so, just like with other conditions that are eligible for MAID.

We must bring together experts and stakeholder groups to define the criteria for access to MAID, especially to distinguish between suicidal thoughts as symptoms and a wish that has been well thought out. A case-by-case clinical assessment is essential.

Questions 19 to 21 pertain to personal views.