BRIEF

TABLED AT THE SELECT COMMITTEE ON THE EVOLUTION
OF THE ACT RESPECTING END-OF-LIFE CARE

August 23, 2021

# Healthcare professionals: at the forefront of medical assistance in dying

FIQ | SECTEUR PRIVÉ

# Foreword

The Fédération interprofessionnelle de la santé du Québec–FIQ and Fédération interprofessionnelle de la santé du Québec | Secteur privé–FIQP represent 76,000 nursing and cardio-respiratory professionals, most of the nurses, licensed practical nurses, respiratory therapists and clinical perfusionists working in Québec health and social services institutions. This strong foundation in the health network enriches their expertise, which is valued and recognized by decision-makers from all over. The FIQ and FIQP is composed of a diverse work experience with various types of beneficiaries who receive services in the health and social services network.

As first-hand witnesses of the healthcare system's daily operations, healthcare professionals see the effects of socioeconomic inequality on health, as well as the impacts of the decisions made at all levels of the political and hierarchical structure. As labour organizations, the FIQ and FIQP represent nearly 90% women who are at the same time healthcare professionals, public and private sector workers and citizens who use the services. Through their orientations and decisions, the FIQ and FIQP strive to protect social gains and to achieve greater equality and social justice.

Driven by their mission, the FIQ and FIQP have always actively participated in the various consultations that have marked the history of Quebec's health and social services system. Whether about bills aimed at modifying the operation or on any other subject that concerns them, the Federations have always defended the interests and concerns of the members they represent, but also those of the population.

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# Introduction

## 1

The issue of the right to die with dignity has been considered, studied, discussed and analyzed for more than 10 years in Quebec, and the population has had the opportunity to express itself on the subject at different turning points in its history. First, during the public consultations of the Select Committee on Dying with Dignity created in 2009, and then when Bill 52 was tabled, leading to the passing of the Act respecting end-of-life care in 2014. The Fédération interprofessionnelle de la santé du Québec–FIQ was present at each of these steps, taking care to consult its delegates and putting forward its recommendations to make elected officials aware of the healthcare professionals' reality.

Since 2014, the reality of medical assistance in dying (MAD) has evolved, both from a legal point of view and from a social and collective point of view. Because the current criteria of the Act limits their access to medical assistance in dying, several people are standing up, speaking out and fighting for access to a death they consider dignified. Some of these battles have ended with rulings that have forced legislative advances at both the federal and provincial levels. In the case of *Truchon v. Attorney General of Canada*, the Court declared unconstitutional the criteria of "natural death that has become reasonably foreseeable" in the Criminal Code and "end of life" in the End-of-Life Care Act.

The number of MAD requests from the population has grown since 2015 and this issue is becoming increasingly important in the public arena[1]. There is social acceptability, and the members of the Federations are no exception. Patients can benefit from MAD and healthcare professionals accompany them and support their loved ones throughout the process. This care is no longer a fantasy, it is now very concrete.. This is why the FIQ and FIQP are pleased to see that elected officials have chosen to continue the collective reflection, in the same spirit that preceded the passing of the Act respecting end-of-life care.

The Federations welcome the National Assembly's creation, on March 31, 2021, of the Select Committee on the evolution of the Act respecting end-of-life care, whose mandate is to address issues related to extending medical assistance in dying to persons who are incapacitated and to persons whose only medical problem is a mental disorder. The Federations, as labour organizations, dedicated to defending its members, but also the patients and the public health network, feel specifically concerned with these issues, because of the importance of the right to die in dignity, and the healthcare professionals' role and expertise in end-of-life care.

Lastly, it is clear for the Federations that the whole issue of resorting to medical assistance in dying is based on a societal choice, which must be made following a very extensive and democratic debate Nevertheless, the nursing and cardio-respiratory professionals have an expertise in end-of-life care which makes them key figures in the concerns and issues that

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[1] Commission sur les soins de fin de vie. *Rapport annuel d'activités du 1$^{er}$ avril 2019 au 31 mars 2020.* [Online], 2020, [https://www.recherchesoinspalliatifs.ca/wp-content/uploads/2020/10/RAA_2019-2020_Commission-soins-fin-de-vie-2020-10-20.pdf] (Viewed July 29, 2021).

arise. Because they have experienced the concrete reality of medical assistance in dying since its implementation, the FIQ and FIQP recently consulted their nurse, licensed practical nurses and respiratory therapist members. Their participation has enriched and supported the reflection already initiated by the Federations and presented in this brief.

# Chapter 1 – Potential extension of medical assistance in dying to incapacitated persons

Since their creation, the Federations have always defended an individual's freedom of choice. In this respect, the individual should be free to make decisions about their own health based on their autonomy, capacity for self-determination, needs and desires, beliefs and values. This applies to a range of issues, such as abortion and vaccination.

This freedom of choice implies considering the ability of the person to consent or refuse care; consent must be free and informed. But what about when the person loses this ability to consent to care because she has a neurocognitive disorder or has been the victim of an accident?

In response to this question, more than 94% of Federation members supported the possibility of making one's wishes known in advance - when one is capable of consenting to care - in the event of incapacity, and this under certain conditions. In fact, members support the idea that a person could give prior consent to receive MAD in anticipation of a diagnosis of a neurodegenerative disease or a sudden accident that would result in serious sequelae, for example.

A majority of the members consulted support a simplified access to MAD. For them, it should not be necessary for the person to have been previously diagnosed with a serious and incurable disease to make the request. The fact that the person meets the criteria at the time should be sufficient for the request to be accepted and for the MAD to be administered, even if the person does not appear to be suffering. Assuming it becomes possible to make an advance request for MAD, more than 96% of the healthcare professionals surveyed want the person who made the request to be able to easily modify or withdraw it. Among respondents, 88% want this advance request for MAD to contain detailed information on the suffering and living conditions that the person anticipates and considers intolerable.

In the current state of the health network and in the absence of investment commensurate with the needs, the Federations wish to reiterate that the request for MAD must in no case be the result of a lack of funding for the care and services of patients and their loved ones. The decision to resort to MAD should always be taken by the person according to his interests, values and what he considers as a dignified end of life, without regard to economic or social considerations.

As first-hand witnesses to the difficulties experienced during the MAD process, the healthcare professionals are concerned by the little support and training available for both patients and their loved ones. Many vulnerable individuals may feel they are a burden to those around them and it is essential to ensure that they receive the support and care necessary for their well-being to avoid slip ups. Moreover, if relatives need to determine when to execute the advance request, they will also need to be accompanied and educated to carry out their role throughout the process.

With all the necessary information, support and funding and according to well-defined criteria, the Federations support extending MAD to incapacitated persons, thereby allowing requests in advance.

# Chapter 2 – Potential extension of medical assistance in dying to persons whose only medical problem is a mental disorder

The Federations have been fighting against all forms of discrimination against individuals since their foundation. They strongly defend the right of equal access for all to care and social services, without distinction or exclusion.

It is in this spirit that the FIQ and FIQP addressed the issue of extending MAD for people with a mental disorder. The removal of the end-of-life criterion opens new possibilities for these people and the Federations welcome the willingness of elected officials to reflect on this and to consult experts on this issue. Mental disorders are a source of suffering in the same way as other pathologies. Hence, it is essential that the persons suffering with a mental health disorder have access to the same care and services as those with a physical health problem.

The healthcare professional members of the FIQ and FIQP who responded to the consultation agreed. They approve of access to MAD for persons whose only medical problem is a mental disorder, but they also have many concerns related to the clinical criteria and prior access to care and services. First, they want a minimum period between the diagnosis and the request for MAD and that the person has at least tried a treatment before having access to it. Then, they believe the person's condition should be assessed by a psychiatrist. They also point out the importance of taking into account the assessment of the person's condition by the multidisciplinary team as part of the MAD request and to ensure he has received all the necessary care and services for his well-being. Moreover, they wonder what the conditions will be for a request to be accepted. Finally, they are concerned about respecting the wishes expressed by the person.

To address these concerns, the Federations and their members want to see a concrete demonstration of real political willingness to increase investments in mental health. To promote a social consensus on the issue of extending MAD, it is essential that the population be reassured about the accessibility and availability of care and follow-up that meet the needs of the individual, throughout the continuum of care. Moreover, several guidelines should be put in place, to suicidal thoughts and the severity, duration and persistence of symptoms. Lastly, having witnessed the fatigue and discouragement of some people accompanying an individual with a mental disorder, healthcare professionals are concerned that training and support be made available to them to prevent their loved one's exhaustion from having any impact on a patient's decision to request MAD.

In the event an Act respecting end-of-life care is amended to allow MAD access to persons with only a mental disorder, the Federations believe it is necessary to consult with experts in the field of mental health to establish clear guidelines, respecting the wishes and values of the person.

# Chapter 3 – Healthcare professionals’ practice in medical assistance in dying

The Law stipulates that the act of MAD must be performed by a physician, i.e., he must administer the MAD to the person whose request has been accepted. The law also stipulates that the physician accompany the person and remain close to him until his death. He will have previously assessed the patient's condition and ensured his free and informed consent. While the guidelines for the medical profession are already well defined, the practice of healthcare professionals deserves to be better defined.

Healthcare professionals have a key role to play in ensuring that end-of-life care is humane and that the patient can die with dignity. According to the consultation conducted by the FIQ and FIQP, the steps in the MAD process performed by the healthcare professionals are the following: answer requests for information and accompany the patients in their formal requests; support loved ones, before, during and after MAD and prepare the patient to receive MAD.

More specifically, the healthcare professional’s roles and responsibilities are done in tandem with the administration of MAD. Most of the time, it is she who acts as a focal point in a patient's case, liaising with the attending physician and other health professionals. She documents the request and informs loved ones how the process works. She assesses the pain, effectiveness of its relief and the patient’s ability to consent. She monitors the symptoms and progression of the disease. She may accompany the patient, upon request, during the MAD procedure. A healthcare professional’s autonomy varies, based on the practice setting. In all cases, as a member of the multidisciplinary team, the healthcare professional supports the loved ones in their bereavement or refers them to another resource offering bereavement follow-up[2].

## SUICIDE PREVENTION

If MAD is made available to persons who’s only underlying condition for a request is a mental disorder, the healthcare professionals will need to align their practice in MAD with their mental health practice, including suicide prevention. In addition to assessing or helping to assess the risk of suicide and establishing a helping relationship to reduce suicidal thoughts, the healthcare professionals participate in directly preventing the person from committing suicide, even against their will[3]. In the context of an imminent and high suicide risk, they may go so far as to break professional secrecy[4]. Is it possible to prevent suicide and at the same time accompany a person who requests MAD because of a mental disorder? The healthcare professionals we consulted were divided on this issue, with some finding these practices entirely reconcilable and others finding them little or not reconcilable. If MAD becomes

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[2] Louis Francoeur and Suzanne Durand. « La loi concernant les soins de fin de vie : Rôles et responsabilités de l’infirmière », *Perspectives infirmières*, Volume 13 No. 1, 2016, p. 56-64.

[3] *Act respecting the protection of persons whose mental state presents a danger to themselves or to others*, Q.L. 1997, c. P-38 001, sect. 6 to 8.

[4] *Professional Code*, CQLR, c. C-26, sect. 60.4.

available to person who’s only underlying condition for the request is a mental disorder, the healthcare professionals would need guidelines on these practices.

**Recommendation 1**

The FIQ and FIQP recommend that a reflection be carried out with specialists, health professionals and healthcare professionals working in mental health in order to specify the guidelines on suicide prevention and on the accompaniment of people who’s only underlying condition for the request for medical assistance in dying is a mental disorder.

## REFUSING TO PARTICIPATE ON THE BASIS OF PERSONAL BELIEFS

Since the first consultations on MAD, the Federations have always defended the healthcare professionals’ right to opt out of this practice if they so wish, without any sanction being taken against them. As medical assistance in dying may represent significant suffering caused by the conflict between individual values and the professional acts they must perform, nurses, licensed practical nurses and respiratory therapists should not be forced to intervene against their personal beliefs under any circumstances. For these reasons, the FIQ and FIQP fully support the principle of the right to conscientious objection under section 50 of the Act respecting end-of-life care. If MAD becomes available to persons who are unfit or who’s only underlying condition for the request is a mental disorder, the healthcare professionals consulted consider it essential to preserve the right to refuse to participate in the MAD because of personal beliefs.

**Recommendation 2**

The FIQ and FIQP recommend that. the right to refuse to participate in medical assistance in dying based on personal beliefs is maintained.

## THE ROLE OF SPECIALTY NURSE PRACTITIONERS

Currently, the Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)[5] sets out that specialty nurse practitioners (SNP), in the same way as physicians, may provide MAD and this practice already exists elsewhere in Canada.

Moreover, in Québec, the Act respecting end-of-life care does not allow SNPs to administer MAD. However, Québec SNPs have all the training necessary to perform the same work as their Canadian colleagues, their training being even the most extensive and advanced in Canada. Like the Collège des médecins du Québec (CMQ)[6] and the Association des infirmières praticiennes spécialisées du Québec (AIPSQ)[7], the Federations believe that the SNP role in MAD should be broadened.

**Recommendation 3**

The Federations demand that SNPs can administer medical assistance in dying.

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[5] *Act amending the Criminal Code and to make related amendments to other Acts (medical assistance in dying),* S.C. 2016, Ch. 3, sect. 2-3.

[6] M.-È Cousineau. « Le Collège des médecins veut que les « superinfirmières » pratiquent l'aide médicale à mourir », *Le Devoir*, [En ligne], 2020, [https://www.ledevoir.com/societe/sante/573735/le-college-des-medecins-du-quebec-veut-que-les-superinfirmieres-pratiquent-l-aide-medicale-a-mourir] (Viewed on July 29, 2021).

[7] Association des infirmières praticiennes spécialisées du Québec (AIPSQ). Mémoire de l'AIPSQ sur le projet de loi 43. Loi modifiant la Loi sur les infirmières et les infirmiers et d'autres dispositions afin de favoriser l'accès aux services de santé. Mémoire présenté à la Commission de la santé et des services sociaux de l'Assemblée nationale du Québec. [Online], 2019, [https://aipsq.com/images/M%C3%A9moire_AIPSQ_-_PL_n43_-_Finale.pdf] (Viewed on July 29, 2021)

# Chapter 4 – Organization of work for healthcare professionals participating in medical assistance in dying

Good organization of work enables healthcare professionals to deliver humane, safe and quality care in a heathy, enriching and rewarding work environment. The organization of work is the immediate work environment in which the healthcare professionals carry out their professional activities. In other words, organization of work determines who does what, when, during how much time, with what support and tools. This organization is essential to the healthcare professionals' contribution to medical assistance in dying.

## CLINICAL SUPPORT

As set out in the Act respecting end-of-life care[8], every institution must adopt a policy with respect to end-of-life care and include a clinical program for end-of-life care. An interdisciplinary support group (GIS) set up in each institution is responsible for giving clinical, administrative and ethical support to the persons responsible for administering MAD. All health professionals, including the healthcare professionals, may refer to this program to find the various protocols suitable for all end-of-life situations. Several training sessions, provided by the Ministry of Health and Social Services (MSSS) and the Ordre des infirmières et infirmiers du Québec (OIIQ), were introduced and offered in the wake of this law going into effect in 2016.

Unfortunately, the responses to the consultation suggest that healthcare professionals are mostly left to their own devices in this type of situation. However, it is necessary for anyone involved in a MAD process to obtain clinical support for their professional practice, in the form of training or otherwise. The consultation revealed that few healthcare professionals have access to training to prepare them for participating in MAD and when it is available, it does not deal specifically with the healthcare professionals' role and remains very general.

A large proportion of respondents would not feel sufficiently equipped to participate in MAD for an unfit person and even less so for a person with a mental disorder. They expressed a need for training in their professional practice and the legal and ethical framework of this practice. Moreover, they also pointed to the need for better inter-professional collaboration in the context of their participation in MAD.

If MAD becomes available to unfit persons or who's only underlying condition to the request is a mental disorder, more than a third of the healthcare professionals consulted even said that under certain conditions, they will refuse to participate in it. To feel at ease in taking part, the conditions identified by the largest number of respondents were: the training, guidelines and collaboration with at least one other health professional. These data reinforce the important need for the healthcare professionals to have clinical support in accompanying the patients applying for MDA and collaborating in its administration.

**Recommendation 4**

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[8] *Act respecting end-of-life care*, Q.L. 2014, c. S-32.0001, sect. 7 to 10.

The FIQ and FIQP recommend that guidelines be developed with the healthcare professionals on a future extension of medical assistance in dying.

**Recommendation 5**

The FIQ and FIQP recommend that the healthcare professionals receive specific training for their participation in medical assistance in dying for unfit persons and persons who's only underlying condition for the request is a mental disorder.

**Recommendation 6**

The FIQ and FIQP recommend that medical assistance in dying is planned in such a was as to ensure the collaboration of at least two health professionals to accompany the patients who makes the request.

### LIGHTENING THE WORKLOAD

The healthcare professionals need time to accompany the patient and his loved ones during the MAD process. However, they are not sufficiently freed up from their other tasks to devote themselves fully to them while still having the time within their regular workday to carry out all their tasks.  Three quarters of respondents pointed out that their workload was never reduced to take into account their participation in MDA. More than half of the healthcare professionals surveyed found that their participation in MDA was never planned. In this context, it appears to be difficult, even impossible, to lighten the healthcare professional's workload by adding the necessary staff, for example.

**Recommendation 7**

The Federations recommend that the participation of healthcare professionals in medical assistance in dying is organized in advance.

**Recommendation 8**

The Federations believe that the healthcare professionals' workload should be lightened to take into account participation in medical assistance in dying.

TIME OFF AND PSYCHOLOGICAL SUPPORT

Although much is said about the emotional dimension that accompanies MAD for the person and their loved ones, much less is said about what it is like for the healthcare professionals. However, accompanying patients and their loved ones during a MAD process is emotionally demanding. This support implies a possible suffering caused by the difficulty to keep enough distance between one's emotions and exercising one's profession in such a context. Therefore, rest and psychological support are necessary for healthcare professionals experiencing these difficulties.

Healthcare professionals who feel the need to do so should be able to take some time off after their participation in MAD. In fact, they many experience difficulties causing a heavy emotional burden especially if there are complications during the administration of MAD. Healthcare professionals should then have the option to take time off work, not being mentally available to the patients in their care. However, the consultation revealed that this option was not always present in their workplaces.

**Recommendation 9**

The Federations demand that the healthcare professionals have the necessary flexibility to take time off work when needed if the medical assistance in dying experience has been hard on them.

Many respondents also demand better psychological support. They raised the possibility of having psychological support before or after administering such care. Failing available psychological support, respondents have even already refused to participate in MAD invoking personal beliefs[9]. These "conscientious objections" do not appear to be due to personal beliefs irreconcilable with participation in MAD, but rather to insufficient psychological support for the emotional burden generated by MAD. Researchers have seen a similar phenomenon in Québec physicians who invoked a conscientious objection in order to be exempt from the administration of MAD[10]. This data demonstrates that accompanying persons requesting MAD

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[9] These three respondents are the number of respondents who reported that they had already refused to participate in MAD the basis of their personal beliefs.

[10] Lucie Opartny and Marie-Ève Bouthillier. « Décoder l'objection de conscience dans le cas de l'aide médicale à mourir. Premiers résultats d'une étude clinique ». *Fédération des médecins spécialistes du Québec* (FMSQ). [Online], 2017, [https://fmsqkiosk.milibris.com/reader/1e5a5fee-68f2-4d92-9673-0532d1703a93?origin=%2Fle-specialiste%2Fle-specialiste%2F2017-12] (Viewed on July 29, 2021).

and participating in its administration are emotionally demanding actions that require psychological support.

**Recommendation 10**

The FIQ and FIQP recommend that psychological support be offered to all healthcare professionals participating in medical assistance in dying.

Given their intimate contact with patients and their loved ones, healthcare professionals play a key role in all stages leading to MAD. In order for them to be able to help people to live the last moments of their lives in dignity, the organisation of work must allow them to devote the necessary time to this. Moreover, healthcare professionals must receive all the clinical and psychological support they need to perform their role.

# Conclusion

Quebec society's opinion on medical assistance in dying has evolved greatly over the past decade, as evidenced by the establishment of the Special Commission on the evolution of the Act respecting end-of-life care. The recent legal battles and following legislative changes have forced a collective reflection on end-of-life care and the current debate on extending medical assistance in dying is generally well received by the population. Both those wishing to avail themselves of medical assistance in dying and specialists on the subject are asking the various governments to take a position on this issue, which is constantly resurfacing in the news. The case-by-case approach cannot be the status quo.

It is impossible to reach a unanimous opinion on the issue of extending medical assistance in dying to incompetent or mentally ill persons. Furthermore, the Federations welcome the willingness of elected officials to listen, inform themselves and take the time to understand the different realities in order to reach a consensus acceptable to society. Several issues need to be considered and the FIQ and FIQP, involved from the beginning, will continue to closely follow the evolution of the *Act respecting end-of-life care* and will participate in all stages to present, among other things, the healthcare professionals' experiences and concerns .

In the event the Act respecting end-of-life care is amended, the Federations can only insist that the contribution of healthcare professionals must be taken into greater consideration to ensure that end-of-life care is respectful and dignified. They must be able to take the time to suitably inform, accompany and provide care. To avoid that the choice of individuals requesting MAD comes from a lack of care, the Ministry of Health and Social Services (MSSS) must be able to guarantee investments to meet its citizens demands. The population is entitled to receive safe, quality care and their decision to use MAD, already difficult to make, must not be based on the existing conditions in the health network.

Because of their close ties with the patients and their loved ones, the nurses, licensed practical nurses and respiratory therapists play a key role in delivering end-of-life care and defending their patients' rights. If they are to collaborate to the extent of their expertise in helping people to live the last moments of their lives in dignity, there must be a willingness to give them their rightful place. Their perspective makes them essential allies in the MAD's multidisciplinary team and their contribution to the debate is indispensable.

# Recommendations

**Recommendation 1**

The FIQ and FIQP recommend that a reflection be carried out with specialists, health professionals and healthcare professionals working in mental health in order to specify the guidelines on suicide prevention and on the accompaniment of people whose only who**’s** only underlying condition for the request for medical assistance in dying is a mental disorder.

**Recommendation 2**

The FIQ and FIQP recommend that. the right to refuse to participate in medical assistance in dying based on personal beliefs is maintained.

**Recommendation 3**

The Federations demand that SNPs can administer medical assistance in dying.

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The FIQ and FIQP recommend that guidelines be developed with the healthcare professionals on a future extension of medical assistance in dying

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