The AQDMD
by Yvon Bureau

For over 20 years, Mr. Bureau has fought for the right to die. He has written and spoken extensively about the right to access special medical assistance, upon request, when a person's end of life is irreversible. He wrote this text to commend the founding of the AQDMD.

There is reason to celebrate the founding of this association today, on September 22, 2007. Its mission is appealing and deserving of citizen involvement. It exists in the name of free will, of dignity and of this ultimate act of freedom.

Across Quebec, my 23 years promoting human rights, responsibilities, and freedoms in a person's end of life have taught me a lot and shaped my convictions and my deepest beliefs.

A person nearing their end of life must be at the heart of discussions and decisions concerning their own end of life. Their dignity depends on this. Their freedom too.

This person has the right to accept, to refuse, and to stop, in part or in its entirety, any end-of-life treatment; this person also has the right to a pain-free death, even if this means hastening death. These rights are well recognized. When it comes to exercising them, however, there is much room for growth. Nearly 95% of people who are dying can end their life within the current legal and moral framework.

Existing legislation allows the person who is ending their life to be more responsible, to be taken more seriously, and to have their wishes respected. The following are some examples of documents that are impactful, that have influence: advance directives for a person's end of life (living will), protection mandates in case of incapacity, notes in a patient's medical file, notes in their care plan. Saying what you want is good, but writing it is so much better! In planning your end of life, this is the best way to take care of yourself, your loved ones, your clinicians, and health facilities.

The most noble act, among health care providers, is to seek free and informed consent from the person nearing their end of life.

Palliative care should be developed, especially in CLSCs, to allow people to die at home or in hospices opened for this purpose. My belief, which I have shared widely, is that active medical assistance in dying should be an exception within the spectrum of end-of-life care. This active medical assistance in dying, when it is allowed by law, is used by less than 5% of patients in their end of life.

In the past, Canadian and provincial palliative care associations were opposed to this active medical assistance that facilitates the act of dying; today, they want to be included in the debate. About 80% of the Canadian population is in favour of this active medical assistance in dying, when a person's end of life is irreversible. This has been the case for more than 15 years. These associations believe that trust in physicians will decrease if medical assistance in dying is made possible, while the opposite is true: trust increases in countries where medical professionals can offer such help.

The concept of dying with dignity has now taken root across Quebec and Canada. This is thanks to the *Responsable jusqu'à la fin* foundation (1986–1996), Dying With Dignity, and other Canadian organizations, palliative care associations and teams, as well as other groups and individuals…

Access to active medical assistance in dying will allow a certain number of people to die with more dignity, and more freely. **We must work towards making active medical assistance in dying allowed by law, administered within a strict and safe framework that is periodically evaluated.** The goal is not to legalize this action, but to have it included in an exemption, through the section 241-b amendment.

We must state, loud and clear, that the following acts need to remain criminal: compassionate homicide, assisted suicide, involuntary euthanasia, and medical assistance in dying that does not meet the strict and safe framework defined by the law.

This potential opportunity will be one of the most important end-of-life assurances. For people nearing their end of life, it will provide more serenity, more days to live, and most importantly, it will radically reduce the rate of suicide within this population; it will prevent so many, so very many tragedies within families, and in society.

We will continue to assist any action and any association that is in support of suicide prevention. We need to use the term "active medical assistance" [in dying] rather than "assisted suicide" and "voluntary euthanasia." These represent two different ways of dying. The primary objective is to allow a person nearing their end of life to die according to their concept of dignity and freedom.

This final act of free will completes the concept of dignity. Our association will therefore work to ensure that this active medical assistance in dying is recognized and, whenever possible, respected.

The organization's members will need to make significant efforts in the fight for recognition; they will need to collaborate and strategize with other associations like ours. Members will become supporters, giving what they can. The AQDMD

should be an association of people who want to work towards this opening in the legislation; they will become members in order to give, more than to receive.

Members should set up events and promotional actions that will have significant impacts (open letters, conferences, actions supporting politicians, etc.). Often, the significance of these impacts will be proportional to our association's credibility in the eyes of our fellow citizens. Moreover, the non-partisan and non-religious nature of the association will serve to bolster its credibility.

The AQDMD's mission must always be greater than the people who lead it. Many achievements have been based on courageous and tenacious humility.

This is something to celebrate and to dream about. Is there life after death? Perhaps. What we know is that a lot of life remains at the end of life. We are building an association for the quality of this end of life!

Yvon Bureau, social worker
Consultant for dying with dignity and freedom