



ASSOCIATION DES  
MÉDECINS PSYCHIATRES  
DU QUÉBEC

**Discussion paper:**

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# Clinical and Ethical Challenges Facing End-of-Life Care

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By the ad hoc Committee on end-of-life care  
Under the aegis of the Association des médecins psychiatres du Québec

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With the collaboration of  
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This discussion paper has been prepared pursuant to the adoption of the *Act respecting end-of-life care*\*<sup>-1</sup> to assist psychiatrists in the work they do. It is neither for nor against medical aid in dying. It should be noted that a good number of the participants interested in developing structures and approaches to be recommended in terms of end-of-life care have reservations with regard to medically-assisted dying. However, society has made a choice and we are committed to creating tools that will help support those people who matter the most to us: namely, patients and their next of kin. The Law and this document do not relieve psychiatrists from the necessary reflection on their own individual positions regarding this question. This document thus seeks to assemble a series of tools that could be used to develop a structured and personalized approach for each patient at the end of their lives. We are proposing a global evaluation process that might appear exhaustive. Indeed, we believe that life and death do constitute a solemn and complex matter, which requires a major investment on everyone's part. Psychiatric assessments and care can make a great contribution to improving the offer of palliative care. It is thus possible that medical aid in dying doesn't materialize for all sorts of reasons other than incapacity; all the more so given that the doctor's goal is above all to provide acceptable relief to the patient's symptoms and suffering. We will advocate an interdisciplinary approach, because we believe that all health care professionals may play an important role, and that since time immemorial, death is a process managed by the group.

We will look at the ethical basis (or "foundations") of the Law and certain relevant definitions in the field of end-of-life care, before drawing a portrait of the contemporary palliative approach and the psychiatrist's place within it. Palliative sedation, a useful and less controversial tool, shall be addressed, as well as medical aid in dying. We will review and comment on the conditions required for the latter to be obtained, the doctor's obligations and the institution that it defines, before approaching the psychiatric assessment, in context. Finally, we shall present some considerations regarding advance medical directives, support, teaching and research measures.

We will examine end-of-life care as only exceptionally incorporating medical aid in dying. All the steps and consultations that culminated in the creation of the editorial committee demonstrated to us that this position is shared by the overwhelming majority of psychiatrists who are interested in this question. Given the newness of this practice, this document will be called upon to evolve over the next few years, based upon our experiences. Several official publications are expected on this subject, including those of the Quebec College of Physicians (CMQ) (evaluation of incapacity, consent to care) and the Ministère de la Santé et des Services sociaux (MSSS), without forgetting the possibility that Canada will legislate on the matter owing to the Supreme Court of Canada's decision in *Carter*, in which euthanasia and assisted suicide were decriminalized on February 6, 2015<sup>2</sup>.

### **The ad hoc committee on end-of-life care under the aegis of the Association des médecins psychiatres du Québec**

\* - An Act respecting end-of-life care, called the Law in the text.

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## 1. INTRODUCTION TO THE ACT RESPECTING END-OF-LIFE CARE

The purpose of the “*Act respecting end-of-life care* (2014, chapter 2) is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy. It seeks to provide them with guidance and assistance that is adapted to their situation as end-of-life patients, notably the prevention and relief of their suffering.”<sup>1</sup>

It includes two major parts: 1) rights, the organization and framework governing end-of-life care, which encompasses the palliative care provided to end-of-life patients and medical aid in dying; and 2) the creation of an advance medical directives register. It will come into force on December 10, 2015. The Canadian Medical Protective Association (CMPA) has invited its members to be prudent with regard to the Supreme Court of Canada’s decision, on February 6, 2015, that “unanimously invalidated the criminal prohibition directed at doctors regarding the provision of aid to someone who is dying and declared it unconstitutional.” The CMPA indicates that “the key fact to keep in mind is that the Supreme Court *suspended the effective date of this declaration of invalidity for 12 months* in order to grant time to Parliament and to the Provincial Legislative Assemblies to legislate, as well as for medical regulatory bodies (Colleges) and medical associations to elaborate policies and guidelines.” For now, it is illegal for anyone, including doctors, to counsel, help, or encourage a person to commit suicide. It issues this opinion for all doctors across Canada, including those in the Province of Quebec, notwithstanding the new *Act respecting end-of-life care*<sup>3</sup>. If Canada does not legislate on the question, it will be up to the Provinces to do so. In the meantime, doctors will have to choose whether they should wait or not for all these legislative ambiguities to be resolved.

To view all the information on the Law, you may visit the Web site:

<http://www.soinsdefindevie.gouv.qc.ca/la-loi>

## 2. ETHICAL PREMISES

Out of a concern for coherence, we have chosen to revisit, in our introduction, the ethical values that the bill upholds, since they have emerged out of a choice made by our society and were given shape with the adoption of the Law. The reader is invited to take a look at Appendix I to explore other ethical challenges that were raised by certain key players who are interested in this question in the Province of Quebec.

The **principles** defended by the Law are as follows<sup>1</sup>:

- Respect for the person at the end-of-life and recognition of their rights and freedoms must inspire each and every act that is carried out towards them.
- The person at the end-of-life must, at all times, be treated with understanding, compassion, courtesy and fairness, with respect for their dignity, autonomy, needs and safety.
- The members of the health care team responsible for a person at the end-of-life must establish and maintain open and honest communications with them.

A dialogue must take place between the patient and their doctor to determine the care that is appropriate to their condition and their values.

- With respect to the **human rights** related to end-of-life care, let's note, amongst others, that:
  - ◊ Any person whose condition so requires is entitled to receive end-of-life care, subject to the particular requirements set out in the *Act respecting end-of-life care*.
  - ◊ Any adult who is able to consent to care may, at any time, refuse to receive care that is necessary to keep them alive, unless specified otherwise in the Law."

It is important to note that in the entire care decision-making process, a dialogue must take place between the patient and their doctor to determine the care that is appropriate to their condition and their values. The question of free and enlightened consent is incontrovertible, since it is necessary in the delivery of all care. According to the Law, this consent may be substituted for all end-of-life care, except in the case of medical aid in dying. The CMQ will be publishing two practice guides, regarding consent to care and evaluation of incapacity, which could shed a certain degree of light on these subjects.

### 3. DEFINITION OF END-OF-LIFE CARE

Here are the definitions set out in the Law<sup>1</sup>:

**End-of-life care:** palliative care offered to end-of-life patients and medical aid in dying.

**Palliative care:** total and active care delivered by an interdisciplinary team to patients suffering from a disease with a reserved prognosis, in order to relieve their suffering, without delaying or hastening death, to maintain the best quality of life possible and to provide them and their next of kin the support they need.

**Medical aid in dying:** care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death. Several people consider this term to be equivalent to that of euthanasia.

**Continuous palliative sedation:** care that is offered as part of palliative care and consists in administering medications or substances to an end-of-life patient to relieve their suffering by rendering them unconscious without interruption until death ensues.

Another definition of care should be added that is not spelled out in the Law, but that is part of palliative care.

**Intermittent palliative sedation:** care that is offered as part of palliative care, that involves the administration of drugs or substances to a person at the end-of-life to relieve their suffering by rendering them unconscious, in an

intermittent manner, while still providing periods wakefulness and meaningful exchanges with next of kin and caregivers.

## 4. INTEGRATED PALLIATIVE CARE

### 4.1 Better understanding the palliative care approach

One of the important premises underlying palliative care is that death is part of life and also deserves a particular kind of attention. The range of palliative care is very varied and is not only intended for patients who are living the last days of their lives. The integrated palliative approach, namely all the care provided in a medical context that is not curative, pursues several targets<sup>4</sup>:

- Open and considerate discussion on the prognosis and trajectory of the disease
- Planning the care beforehand
- Psychosocial and spiritual support
- Relief of pain and symptoms

This approach promotes autonomy and respect, care focused upon the person and their family, integrated holistic care, equitable access to health care and an effective use of health care resources.

At the beginning of a disease, most patients prefer increasing their lifespan with treatment, notwithstanding the loss of certain functions or the presence of pain. With time, for several people, maintaining their cognitive faculties and their mobility may become more important. The intensity of care may then decrease, as their lifespan is no longer the overriding goal. That said, palliative care that is properly administered does not shorten a person's life<sup>5</sup>. Currently, palliative care in Canada is not deployed commensurate to the needs that exist, and the ageing of the population will add to this challenge. Despite everything, we believe that all doctors should begin a discussion with their patients on their values and wishes with regard to their health when they are in good health, and continue said discussion throughout their lives. They will then discuss the prognosis, as well as invasive and non-invasive treatment options, while examining the risks and benefits of each alternative.

Palliative care has enabled human beings to die with dignity for many years now. It is thus expected that the Government's new sensitivity to the case of patients who are seriously ill or dying will provide a way to financially support the development of palliative care units and interdisciplinary teams in hospitals and for the home, as well as for the teaching of the integrated palliative care approach in all health care professional groups. Unfortunately, such support is still taking a long time to materialize in a way that lives up to the expectations of the professionals involved in the field<sup>6</sup>. According to the report done by Senator Carstairs in 2010, only 18% to 30% of patients have such access<sup>7</sup> across Canada.

To date, the reception given to the *Act respecting end-of-life care* has been rather

Palliative care has enabled human beings to die in dignity for many years now.

reserved in the palliative care milieu, that considers that medical aid in dying was not necessary for being able to offer quality end-of-life care, and that it cannot be the only solution for improving the care provided to patients who are

dying<sup>8</sup>. In this document, we choose to address end-of-life care that will exceptionally integrate medical aid in dying, since the options already offered by palliative care are able to respond to the very overwhelming majority of needs. The modification of the care objectives, the cessation of treatment, the use of opiates in increasing doses, up until relief and continuous or intermittent palliative sedation remain available and relevant.

It is very important to be aware, because a recent Canadian study revealed that only 54.2% of doctors and nurses believed that the cessation of a treatment susceptible to extend a patient's life at the patient's request was permitted, and 82.7%, with regard to the use of opiates adjusted to providing the relief of symptoms<sup>9</sup>. However, for 20 years now already, these two practices are explicitly permitted in Canada<sup>10</sup>.

## 4.2 The role of psychosocial palliative care

In the Law, article 4 specifies that "Every<sup>1</sup> person, whose condition requires it, has the right to receive end-of-life care" and, article 7, that "Any 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." This article also stipulates that "For this purpose, an institution must, among other things, establish measures to promote a multi-disciplinary approach by health and social services professionals and the collaboration of the various other resources concerned who provide services to its users."

Cecily Saunders<sup>11</sup>, one of the founders of modern palliative care, draws attention to the challenges represented by moral pain, associating it to the notion of "total pain". This concept lays bare the complex and substantive psychological, physical, spiritual and social experience that occurs at the end-of-life.

Quality palliative care requires all caregivers involved to possess a competence and expertise in each of these sectors, coupled with an interdisciplinary evaluation and intervention. Increasingly numerous publications and recent reference books, such as the "Handbook of Psychiatry in Palliative Medicine" by Dr. Harvey Max Chochinov and Dr. William Breitbart<sup>11</sup>, confirm the development of an understanding of this interface between the body's experience and the psychological and psychosocial state of an individual, which provides insight in developing an increasingly satisfactory response to these needs.

Nurses, psychologists, social workers and spiritual counsellors are the key players in the evaluation of the needs and agony of a person at the end-of-life. They are part of the basic palliative care team, although some centres are fortunate in being able to count upon several other kinds of professionals. The skills of the various practitioners are generally deployed in ten key fields<sup>12</sup> according to the MSSS:

- Pain and symptoms
- Psychosocial and spiritual needs
- Needs related to the organization of daily living
- Agony and death
- Mourning
- Communication
- Collaboration focused upon the person and their next of kin
- Ethical and legal questions
- Personal and professional development
- Palliative care and organization of health care

Their respective areas of skills are summarized in the following table. Obviously, in teams that do not enjoy the entire range of all these professionals, the skills can be redistributed.

**Table 1:**  
**Professionals in palliative care and their specific skills<sup>12</sup>**

Professional	Specific skills
Doctor	<ul style="list-style-type: none"> <li>• Evaluate and treat pain and symptoms.</li> <li>• Diagnose, make a prognosis and determine the therapeutic options, and explain them in layman's terms to the patient and their next of kin.</li> <li>• Ensure a presence and a frequency of visits that is adapted to the patient and their next of kin's needs.</li> <li>• Evaluate with the patient and their next of kin the care objectives and plan these in cooperation with the team based upon the prognosis.</li> <li>• Prescribe non-pharmacological and pharmacological approaches taking into account their benefits and drawbacks.</li> <li>• Assemble all the relevant data from all the members of the team to co-ordinate their work.</li> <li>• Escort the next of kin in the mourning process.</li> </ul>
Pharmacist	<ul style="list-style-type: none"> <li>• Revise the effective and ineffective pharmacological interventions, so as to put forward a targeted treatment plan.</li> <li>• Optimize the pharmacological plan in accordance with the care objectives and the patient's functional limitations.</li> <li>• Attempt to limit undesirable side effects, and relieve them when they cannot be avoided.</li> </ul>

Professional	Specific skills
Nurse	<ul style="list-style-type: none"> <li>• Observe the pain and symptoms and take action in accordance with the care plan.</li> <li>• Observe and evaluate the psychosocial and spiritual needs of the patient and their next of kin and, if needed, refer the patient to a social worker or spiritual counsellor.</li> <li>• Provide support to the patient and their next of kin daily, adapting it to the evolution of the situation.</li> </ul>
Orderly	<ul style="list-style-type: none"> <li>• Observe the manifestations of pain and discomfort and report on them, if necessary, to the nurse.</li> <li>• Provide assistance and care to make the patient comfortable.</li> <li>• Seek to maintain the patient's functional capacities and assist them in their limitations.</li> </ul>
Psychologist	<ul style="list-style-type: none"> <li>• Perform psychological assessments and interventions in a context of pain and overall suffering.</li> <li>• Evaluate the adaptation capacity of the individual and their next of kin and take psychotherapeutic action to foster their adaptation.</li> <li>• Assist the patient in dealing with the end-of-life and its symbolism.</li> <li>• Provide psychotherapeutic support to the next of kin in mourning.</li> </ul>
Social worker	<ul style="list-style-type: none"> <li>• Recognize the impact of pain, the symptoms and the treatments upon the person and their next of kin and that the person's experience can influence the treatment of pain and its symptoms.</li> <li>• Observe and evaluate the psychosocial needs of the patient and their next of kin.</li> <li>• Support the patient and their next of kin in their adaptation to the disease and the numerous losses that they will have to deal with.</li> <li>• Support the person and their next of kin in the search for and use of available resources and support.</li> <li>• Escort the next of kin in the mourning process.</li> </ul>
Dietitian, nutritionist	<ul style="list-style-type: none"> <li>• Support the patient and their next of kin with regard to the food to be eaten at the end-of-life.</li> </ul>
Occupational therapist	<ul style="list-style-type: none"> <li>• Relieve discomfort and pain.</li> <li>• Prevent and treat bruises and sores.</li> </ul>

Professional	Specific skills
Occupational therapist (continued)	<ul style="list-style-type: none"> <li>• Observe and evaluate the psychosocial needs of the person and their next of kin and respond to them by encouraging the achievement of realistic and worthwhile goals related to their daily activities.</li> <li>• Foster the maintenance of the patient’s functional capacities.</li> <li>• Ensure the safety of the patient and their next of kin.</li> <li>• Make it easier for family caregivers to take charge of caring for the patient.</li> <li>• Help the patient to remain in their natural living environment as long as possible, and even until their death.</li> </ul>
Physiotherapist	<ul style="list-style-type: none"> <li>• Relieve pain and discomfort.</li> <li>• Foster the maintenance of the patient’s functional capacities.</li> <li>• Ensure the safety of the person and their next of kin.</li> <li>• Make it easier for the family caregivers to take charge of caring for the patient.</li> <li>• Facilitate homecare.</li> </ul>
Spiritual counsellor	<ul style="list-style-type: none"> <li>• Recognize the impact of pain, the symptoms and treatments on the person and their next of kin.</li> <li>• Support the person and their next of kin in terms of their spiritual and religious needs.</li> <li>• Be attentive to the expression of the needs related to the organization of daily living and end-of-life.</li> <li>• Support the next of kin in the mourning process.</li> </ul>
Volunteer	<ul style="list-style-type: none"> <li>• Be attentive to the patient’s physical and psychological experiences and evaluate with them how they wish to be helped and then seek out the necessary assistance.</li> <li>• Be available to listen to the patient and their next of kin, and offer them assistance, when possible.</li> </ul>

Numerous teams also benefit from the collaboration of psychiatrists, whose role will be discussed in the following section.

## Clinical vignette: n° 1: Anxiety and interdisciplinarity

Ms. X, 52 years old, has just been admitted into the palliative care unit on account of a breast cancer that is evolving aggressively, with complications including meningitis. Upon her arrival, she expresses a very strong desire to die. Her suffering is huge. The various caregivers examine the symptomatic, relational and material dimensions of her situation. They draw a picture of the situation at a team meeting and take action, each member according to their respective skills.

The anxiety symptoms are tremendous. The psychiatrist prescribes 0.5 mg of lorazepam 3 times a day with interdoses of 0.5 mg, if needed. The nurses administer the PRN, as soon as the patient manifests the need. The psychologist has uncovered a stressful relationship with a meddling disabling mother, who often puts religion at the centre of their exchanges, while the patient does not share these values with her mother. In therapy, the patient is able to view a more nuanced image of her mother and feels capable of taking what is good in her and putting aside those things that don't agree with her. The patient accepts that her mother come to visit her from abroad. In her presence, the diligence of the orderlies in ensuring the patient's personal care means that the mother doesn't intervene and the patient feels that her privacy is preserved.

When her children come to visit, the orderlies set up a table and a card game around which the family has a good time. The members of the personnel know them by name. They have collected relevant clinical data, but also know how to cheer them up with jokes that lighten up the ambience. It's not uncommon to hear a burst of laughter coming out of the room.

Substantial concerns about the sale or bequest of some material goods, almost obsessive from the beginning of the stay, are dealt with by the social worker who makes it easier for the notary to come to the hospital. Some property is divided up between the next of kin, others are put up for sale. Progressively, the patient is led to accept to cede this responsibility to her older daughter, thereby recognizing her adult role and capacity to take over from her. In addition, with the psychologist's help and with the revelation of the trust that she has in her children, she succeeds in somewhat attenuating some of her bitterness towards their father who was very disappointing. Throughout the three weeks of her stay, the palliative care doctor adjusts the analgesia and at the end-of-life, when her breathing becomes difficult, the doctor administers continuous palliative sedation.

This vignette illustrates that the suffering at the origin of a desire to die was made up of several factors that deserve to be nuanced and treated adequately. It shows that the imminence of the end does not stand in the way of important life stages to be navigated that can lead to significant psychic developments being achieved and, by the same token, provide a degree of relief to the patient. We also see in the preceding vignette that a shared vision of a person's dignity — by way of respect for their identity, a certain knowledge of their life's trajectory, and respect for their privacy gives rise to a favourable climate, fosters

the development of a relationship with the team and provides the latter with the feeling of a job well done. The rapid administration of anxiety-relieving drugs stems from a culture of care that seeks foremost the recognition of the symptom and its relief. The popular perception according to which it is better to manage one's anxiety alone, or that benzodiazepines are a crutch, or that they generate a dependency, no longer constitutes an obstacle to treatment.

## 5. PSYCHIATRISTS AND END-OF-LIFE CARE

### 5.1 The role of psychiatrists in palliative care

Palliative care shares with psychiatry and the psychosocial sciences their interest in people's physical or psychic suffering, and especially their interrelationships. The end-of-life experience simultaneously involves a psychic experience that is worthy of being coped with and shared, but also psychopathologies that play a significant role in suffering and in the individual's needs. Such work directly relates to the psychiatrist's traditional expertise and understanding of the psychiatric complications that are linked to chronic disease, particularly when the prognosis is finite<sup>13</sup>.

The psychiatrist's role in palliative care is performed vis-à-vis the patient, their next of kin and the team so that it will foster the integration of the knowledge pertaining to the psychosocial challenges, so as to help relieve suffering as a whole. They may also collaborate in educating and training palliative care personnel to help them improve their communications and intervention skills with the person at the end-of-life and their next of kin.

Several psychiatrists around the world have contributed significantly to developing knowledge about the psychiatric complications that arise at the end-of-life and their treatment: collaboration in research and teaching also remain an important task.

The psychiatrist's role with the patient includes the following interventions<sup>11</sup>:

- Diagnose psychiatric disorders such as depression, anxiety disorders and neuropsychiatric disorders, including delirium. These three complications are the ones that appear most frequently in palliative care<sup>14</sup>.
- Diagnose other psychiatric disorders such as psychotic disorders and evaluate their impact upon the end-of-life person's situation and suffering.
- Identify the personality traits or disorders so as to reinforce the patient's strengths and to identify their vulnerabilities and the adaptation mechanisms that they may possess. The psychiatrist's expertise in exploring the patient's emotional experience in relationship to insight into the person's development will make it easier to build more functional relations and enable the team to put an intervention plan into place that is adapted to each individual.
- Recommend non-pharmacological interventions, including psychotherapy to improve the quality of life and diminish the suffering of the person at the end-of-life.

The psychiatrist's role in palliative care is performed vis-à-vis the patient, their next of kin and the team so that it will foster the integration of knowledge pertaining to the psychosocial challenges, so as to help relieve suffering as a whole.

- Recommend pharmacological interventions that take into account the end-of-life context and any possible interactions between different medications.
- Evaluate the patient's decision-making capacity faced with a particular situation.
- Facilitate the understanding of the physical disease as such and the functional adaptation mechanisms that are present or not, so that the care being provided can be adapted.

In their role with the team, they are called upon to:

- Foster the team's understanding and its assimilation of the psychiatric challenges and issues at hand.
- Reduce the personnel's distress by guiding them towards interventions that are adapted to the psychiatric context, as this expertise is not often solicited by the personnel in the primary teams.

Seeing as the goal of all caregivers is to relieve suffering and to accompany the patient in their situation, the psychiatrist must be available in every situation that comes under their competence, and not only with regard to requests for medical aid in dying. *In our point of view, such a restrained commitment would breach the principles of equity and access to care.* We will also address the psychiatrist's role in the section on medical aid in dying.

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## 5.2 Pharmacological and non-pharmacological psychiatric interventions in palliative care

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### 5.2.1 Psychotherapy and palliative care

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The potential benefits of psychotherapy are all too often still underestimated in palliative care. Its positive effect upon survival has not been demonstrated, in contrast to that of general palliative care. On the other hand, its effects upon improving depression or anxiety symptoms, existential distress, psychic suffering in general and the quality of life have been substantiated by various studies undertaken amongst this population<sup>13</sup>.

Its application does however require an adaptation to the person's physical condition that can limit the length of the sessions, as well as the patient's investment in the process. In this context, lengthy therapies such as interpersonal therapies or classic cognitive behavioural therapies, as well as psychodynamic-themed approaches are, generally speaking, more difficult to apply, which is not a contraindication in and of itself. Supportive therapy, which implies active listening, interventions for clarification and support, as well as occasional interpretations, is validated and effective, notably in a context of depression.

Innovative approaches have been developed to more specifically target symptoms that play a role in psychic suffering, notably existential distress and demoralization. Demoralization is a concept that was elaborated by the Australian psychiatrist David Kissane<sup>15</sup>: it encompasses despair, loss of one's senses and existential distress, which generates ideas about death (passive, suicidal or others) amongst people who are suffering from a serious disease.

**Table 2:**  
**The types of psychotherapies in palliative care**

Approaches specifically validated in palliative care
Supportive psychotherapy Interpersonal therapy Cognitive behavioural therapy Group therapy Relaxation Behavioural approaches
Innovative approaches in development and validation
Cognitive-existential therapy Therapy focused on searching for meaning Therapy pertaining to dignity Therapy to manage cancer and live in peace (CALM) Narrative therapy Hypnotherapy

The overall goals of psychotherapy in palliative care are focused upon the following elements<sup>13</sup>:

- The integration of end-of-life into a continuum of experiences, along with its various perceptions, that sometimes require adjustments for the patient;
- The creation of a link and an alliance to reduce feelings of isolation;
- The preservation of the values of humanity and self-esteem faced with death;
- The exploration of loss and separation to come; and
- The stimulation of the personal resources that are available and that have already been used for adaptation during one's life.

Psychotherapy can be effective when it is adapted to the context of palliative care, notably to its physical reality and particular themes. Severe existential distress, depression and anxiety symptoms are frequent components of suffering at the end-of-life, although the definition of suffering remains vague and gives rise to some controversy. In this regard, its sustained presence will diminish the perceived value of life and leads to requests for assisted suicide, euthanasia and medical aid in dying all over the world, notwithstanding the difficulty caregivers may encounter in evaluating the preceding in an objective fashion. It may become intolerable when it is complex,

Psychotherapy can be effective when it is adapted to the context of palliative care, notably to its physical reality and particular themes.

underestimated, or not treated adequately. Accordingly, an understanding of suffering therefore requires an exhaustive evaluation of its components: physical, psychological, emotional, social, or existential. Only an assessment of all these factors, their understanding and their treatment can help diminish this experience of jeopardizing an individual's integrity<sup>11</sup>.

Dealing with this suffering in psychotherapy can have a considerable impact upon the person and their next of kin. Doctor Harvey Max Chochinov is eloquent on this subject<sup>16</sup>: he talks about certain clinical situations where an intervention in therapy on dignity modified patients' approaches to death or eradicated requests for a rapid death, although such a result is unforeseeable and is not a goal in itself.

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### 5.2.2 Other non-pharmacological interventions in palliative care

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The non-pharmacological approach also implies providing in the care plan for each patient to have customized measures to guide the caregiver team. Interventions should be targeted towards a psychological symptom or behaviour and associated with specific needs. By anticipating, or indeed by preventing certain patient reactions, the experience of care for the patient, their next of kin and the team can become far more satisfying.

Beforehand, the professional who drafts the care plan — depending upon the teams, the nurse, psychologist or doctor (very often the psychiatrist) —, takes the time to collect data from the caregivers, third parties and the patient in order to define the symptoms or behaviours that are present, to quantify them and then make a diagnosis. Measures can then be implemented to better fulfil the patient's needs, make it easier for the latter to adapt to their milieu by modifying the environment according to their physical condition and capacities, but also by taking the patient's personality into account.

Palliative care teams or other medical services are not necessarily used to dealing with patients who have personality disorders or various psychiatric problems. Also, drafting an interdisciplinary care plan that is filed in the dossier and the presentation of this plan to the care team members in order to discuss it is a very useful exercise. Cohesion between the team members on all the shifts should be encouraged so as to enable constant and effective interventions. Sharing information and teaching the next of kin and the caregivers, as well as providing support must likewise be favoured.

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### 5.2.3 Psychopharmacology that is particular to palliative care

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The thinking that underlies the choice of a psychopharmacological intervention in palliative care is rooted in the treatment of the major psychiatric syndromes, but also

in a more symptomatic approach. Indeed, the symptomatic approach seeks primarily to improve the patient's quality of life through an optimal control of the symptoms in terms of their intensity and in a timely fashion, based upon the prognosis, as the latter contributes to the experience of suffering at the end-of-life. When used in a manner that is adapted to the palliative context, psychotropic drugs can provide relief. Even though classic research methodologies, such as randomized controlled research give rise to special kinds of clinical and ethical challenges in palliative care, literature has been written on the specific use of psychotropic drugs in the treatment of psychiatric disorders. Depression and delirium continue to be the disorders that have been studied the best. While the data on treating anxiety disorders other than with benzodiazepines remains rather weak.

Psychotropic drugs play a major role in palliative care treatment. Generally speaking, about 50% of people who receive palliative care will receive at least one psychotropic drug, often for reasons other than psychiatric purposes<sup>17</sup>. Their use is targeted at treating insomnia and anxiety, disorders such as depression or delirium, but also physical symptoms, such as pain, nausea and vomiting, anorexia and cachexia, as well as fatigue, for which a literature covering a variety of clinical tests is available.

People who receive palliative care are often older, with the physiological changes that accompany ageing. They are often undernourished and have lower levels of hydration and diminished kidney function. Their cognitive functions are often altered by disease and polypharmacy, which is often necessary. Drug interactions with the cytochromes P450, 3A4 and 2D6 are particularly frequent.<sup>14-18-19</sup>

The choice of psychotropic drugs will be influenced by a series of additional factors:

- The physical symptoms that are present, so as to favour medications that have multiple effects (killing two birds with one stone).
- The estimated survival of the individual, to take into account how much time the selected molecules need to act. The suggested use of psychostimulants or more recently, of ketamine, as a treatment for the symptoms of depression and depression in an end-of-life situation is one example.
- The possible routes of administration, given that the oral delivery of medication can become more difficult, indeed impossible at the very end-of-life. This tends to particularly favour the use of benzodiazepines and first generation neuroleptics, because they are available in a parenteral formulation.

Taking these elements into account, it then becomes possible to exercise an optimal control over psychiatric symptoms, but also the physical ones, thereby reducing suffering. The psychiatrist's skills and experience regarding the use of psychotropic drugs, their effectiveness and their side effects, are thus an additional expertise that is most appreciated.

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## 5.3. The approach to specific psychiatric disorders

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### 5.3.1 Depression<sup>20</sup>

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Depression in palliative care is under diagnosed. This can be explained by the fact that it is often considered a normal reaction to a serious illness, that one avoids looking directly at it by offering words of encouragement or then again by focusing upon the physical symptoms, rather than confronting the moral torment that underlies the patient's condition. Meanwhile, the patient who fears overwhelming the people around them or appearing weak, will often tend to keep the symptoms to themselves. The doctor may also fear inflicting side effects upon the patient by prescribing antidepressants or even raising the issue of suffering without being able to provide appropriate support. It is estimated that 5% to 20% of palliative care patients suffer from depression<sup>11-21</sup>. Analogue scales or brief questionnaires could help the teams with screening<sup>22</sup>.

The somatic symptoms of depression — loss of appetite, insomnia or hypersomnia, fatigue, difficulties of concentration — are very often present in terminal diseases. The clinician will thus have to grant more weight to the other symptoms. Pervasive anhedonia without responsiveness vis-à-vis one's next of kin strongly suggests a major depressive episode. The same would be true with regard to guilt that is generalized, a negative evaluation of one's life at the end-of-life without any galvanizing elements, an overriding perception of being a burden, as well as suicidal thoughts. In this phase of life, being female no longer constitutes a risk factor for major depression. Youth, a life that is being cut short and concerns about the future of one's children make young adults more susceptible to depression. A previous history of depression remains potent, although most episodes that occur in palliative care are isolated episodes. When the disease begins, social support plays a rather protective role against depression. With the individual's physical decline, the feeling of being a burden on their next of kin, clearly associated with depression and suicidal thoughts, may give rise to the relational network becoming an additional concern. Meanwhile, pain generates a reciprocal relationship with depression. It increases the risk, but we also know that depression increases the perception of pain. The same is true for fatigue. Certain tumour sites such as the pancreas, the breasts and the oropharynx are more associated with depression. We also know that nervous system tumours and certain hormone-secreting tumours can induce depression. Corticosteroids, several chemotherapy agents (vincristine, vinblastine, asparaginase, intrathecal methotrexate, interferon and interleukin), as well as certain radiotherapy protocols can trigger a depressive episode.

Let us now turn to treatment. Supportive therapy has won wide acclaim here, as it is characterized by a flexibility that adapts better to the patient's physical condition and their level of energy. It remains the primary recommended psychotherapeutic intervention as a result of a meta-analysis conducted by the Cochrane group<sup>23</sup>. It is not necessary to have a solemn demeanour, despite the imminence of death; an open and compassionate attitude, as well as sustaining a relaxed dialogue, indeed a little buoyant at times, will facilitate the therapeutic relationship and will enable the patient to share their concerns about their end-of-life and not only with respect to death.

Although associated with depression, denial is not uncommon<sup>24</sup>. It can be adaptive or even culturally approved: however, it should be addressed with ingenuity and respected in view of the protective role it plays or enlisted without confrontation. A lot of active listening, validation, and importance granted to the patient's life trajectory and identity, a few interpretations that can be suggested, perhaps shorter conversations, faced with the comings and goings of the personnel and visitors: this is what really counts. Cognitive and behavioural therapies, imaging, hypnosis, biofeedback and relaxation can more specifically target pain or anxiety-depression symptoms.

The pharmacological treatment of depression in palliative care draws its recommendations from studies conducted amongst populations with cancer<sup>25-26-27</sup> or other physical health problems<sup>28</sup>. Many of them are based upon the treatment of symptoms, rather than upon the diagnostic entity as such.

Several practitioners prefer psychostimulants in view of how fast they act and their favourable influence upon cognition. Their short acting nature, about 4 hours, their regular forms enable, for example, to program them to be taken as a function of the visiting hours. Initial doses of 2.5 mg to 5 mg in the morning and at noon of methylphenidate or dextroamphetamine can be titrated every 5 to 7 days. Insomnia, increased blood pressure, or trembling may occur. A loss of appetite is rare with these patients. The exacerbation of twitching, dyskinesia and confusion have to be monitored. Generally, doses of under 15 mg are sufficient.

Antidepressants are all equally effective. Their side effect profile guides the choice that is made. Most selective serotonin reuptake inhibitors (SSRIs) have little affinity for adrenergic, cholinergic, or histaminergic receptors. This reduces the risk of hypotension, urinary retention, constipation, sedation and cognitive problems that one may see with the use of tricyclic antidepressants. It is often wise to avoid fluoxetine and its long half-life. Digestive discomfort, insomnia, agitation and sexual dysfunction have to be monitored.

Venlafaxine, desvenlafaxine and duloxetine can reduce neuropathic pain. These drugs like the SSRIs involve a risk related to withdrawal reactions when one stops taking them abruptly. Trazodone is often used as a sedative at doses ranging from 25 mg to 100 mg. It may give rise to hypotension. Mirtazapine can have a positive effect on insomnia and a person's appetite. It also spares one's sexual functions. Bupropion is also characterized by this advantage and the dopaminergic effects that are susceptible to reducing one's fatigue. It is not advisable for patients at risk for seizures.

Tricyclic antidepressants are effective in treating neuropathic pain. In addition to the side effects referred to above, they are associated with arrhythmia. Amongst them, the secondary amines (nortriptyline and desipramine) should have precedence with the use of initially weak doses (10 mg to 25 mg) that can then be increased after a few days. Doses from 25 mg to 125 mg are often sufficient in this kind of population.

Ketamine could be an alternative of choice in view of how fast it acts in this population as seems to be revealed in certain recent case studies. A randomized study is under way in Europe. The approach<sup>29-30</sup> is recent and we are unable to make any precise recommendations at this stage of the exercise.

### 5.3.2 Anxiety disorders<sup>11</sup>

For the psychiatrist who works in terminal care, an assessment of anxiety symptoms is frequently the reason behind requests for a consultation<sup>31</sup>. Much more than a disorder, it is a symptom associated with host of conditions where research into its etiology can help point the way to an appropriate treatment. Here, as is the case with depression, sociodemographic risk factors disappear in the presence of serious disease. Seeing as its manifestation is often more somatic, the detection threshold of the medical teams is quite high. It can be enhanced by raising people's awareness about its emotional and cognitive dimensions through the use of specific instruments that will ultimately pave the way towards an adapted care plan, which can foster the patient's quality of life.

The most frequent form is probably trait anxiety that we hesitate to describe as an adjustment disorder given that it is difficult to make a judgment on the atypical nature of the picture when confronted with the challenges in a terminal case. Its uncomfortable nature and the intensity of the suffering associated with it are important clinical signposts in determining the most appropriate intervention. The fear of death, of pain, of dependency, apprehension related to the future of one's next of kin can generate a pageant of catastrophic thoughts, generalizations and somatic symptoms: shortness of breath, chest tightness, diaphoresis, palpitations, muscle tension, insomnia, etc. Certain classic anxiety disorders such as panic disorder may appear for the first time in an oncology or palliative context. Confinement, as a precautionary measure for microbiological reasons or in radiotherapy machines can ignite a pre-existing disorder or generate a first crisis. Generalized anxiety disorder, in these turbulent situations where medical, financial and interpersonal stress follow one another, are not uncommon. Specific phobias such as vomiting or sleeping (and to stop breathing while sleeping) may also occur. Even experiences associated with the diagnosis, with certain treatments or chemotherapy can take on the form of post-traumatic stress syndrome<sup>32</sup>. If they existed beforehand, these syndromes can obviously be exacerbated under these conditions. Obsessive-compulsive disorder can likewise undergo the same evolution with an immunocompromised patient who will have to multiply their precautions to not be contaminated.

Anxiety very often plays a role in depression and delirium. Likewise, one will more often see anxiety disorders due to a patient's general medical condition. Rushes of anxiety often accompany a deterioration of a person's medical condition, especially when respiratory problems are involved, such as pulmonary embolism or bronchospasms.

Certain drugs such as corticosteroids, psychostimulants, sedatives and sympathomimetic bronchodilators can generate anxiety. In the case of corticosteroids, the relation is dose-dependent and can even give rise to psychoses, manic agitation or mixed moods. Inadequate or insufficient treatment of pain can give rise to a well-known clinical picture. The patient appears tense, agitated, sweats and complains about pain whenever they can. Suicidal thoughts are not uncommon. That is why the use of long-acting pain relievers along with interdoses are favoured, rather than short acting ones whose use is often accompanied by painful exacerbations of suffering, especially if they're only being prescribed as needed. Short acting anxiolytics can also

give rise to the phenomenon of rebound anxiety, whose chronology will be regular, if medication is taken at set times of day (alprazolam, in particular, can give rise to this phenomenon). Akathisia is not rare. Antinauseants, such as prochlorperazine, metoclopramide and domperidone are dopaminergic blockers that can give rise to this extrapyramidal side effect. A dose reduction and the addition of benzodiazepines, beta blockers or antiparkinsonians may then be of great assistance.

Withdrawals from alcohol, opiates, benzodiazepines, corticosteroids, nicotine and anticonvulsants may give rise to agitation situations. The abrupt cessation of these drugs or substances, during episodes of medical deterioration or during advanced terminal phases, when more sporadic vigilance can undermine the patient's taking their oral medication, thus requires special attention so that it doesn't lead to uncomfortable anxiety symptoms.

In terms of psychotherapy, the same general principles apply as in the case of treatments for depression. The therapist has to get actively involved and not hesitate to give advice or become the patient's advocate in order to help them resolve practical and concrete problems that contribute to their suffering. Frank discussions with regard to the patient's fears and anxiety regarding death have been demonstrated to be exercises that relieve anxiety. Spiegel<sup>33</sup> describes this as a kind of "detoxification" and demystification of the experience of death that is able to reduce psychological distress. Light to moderate anxiety often responds to psychoeducation and sharing clear information that is respectful vis-à-vis what the patient wants or doesn't want to know about their situation, their future and the emotional reactions that they are likely to experience. The participation of their next of kin adds to the effectiveness of such interventions. In the cases where anxiety is more persistent and invasive, benzodiazepines represent a first line of treatment. Often lorazepam, oxazepam and temazepam are favoured on account of their metabolism through hepatic conjugation that is less subject to interactions. Benzodiazepines can have an antiemetic effect, particularly when vomiting recurs and plays a role in a patient's anxiety. Longer acting benzodiazepines such as clonazepam can provide more continuous relief. The fact that these drugs can inhibit normal respiratory function makes their use more delicate in certain cases. Non-benzodiazepine sleeping pills, such as zaleplon and zopiclone may be used, as well as antihistamines such as diphenhydramine or weak doses of atypical antipsychotics. However, on account of their unique effectiveness, one will often choose to use benzodiazepines, even in these cases, while titrating them very carefully<sup>34</sup>. One must also be sceptical about the anticholinergic effects of antihistamines, as is the case with the extrapyramidal side effects and hypotension that is associated with certain antipsychotics. SSRI's and venlafaxine can be used for anxiety disorders, such as post-traumatic stress syndrome, panic disorders and generalized anxiety disorders, but the sometimes longer time they need to take effect has to be taken into account. Any use of tricyclic antidepressants has to be accompanied by the same precautions, as those described in the previous section.

### 5.3.3 Severe and persistent disorders

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Severe and persistent disorders, such as schizophrenia, do not exclude the capacity to consent to certain kinds of care and this, even though they are under protective supervision. Patients with persistent disorders are often the subject of prejudices both in the general population and within medical teams. The reality of these disorders in a general health care context is often one of exclusion, neglect or paternalism, due to misconceptions or a lack of training. Because they are isolated, poorly treated, or because one fears disturbing them even more, one often avoids approaching them with regard to end-of-life challenges and issues. Nevertheless, their concerns are the same as everyone else. One of the rare studies, done in the U.S., with regard to the documentation on the end-of-life concerns of people with psychiatric disorders reveals in point of fact themes that match those expressed by the general population: the desire to live and extend one's life, the notion of being a burden on one's next of kin or financial preoccupations, symptoms such as pain and the desire to say one's goodbyes<sup>35-36</sup>. It was also demonstrated that these people are capable of tolerating these subjects being addressed<sup>37</sup>. It may sometimes be useful to begin by presenting them vignettes, for example, a case of someone in a coma or with terminal phase pain associated with a metastasized cancer and to have them think about it and express themselves hypothetically, before asking them what would be their decision in such a situation. The Web site [www.promotingexcellence.org/mentalillness](http://www.promotingexcellence.org/mentalillness) provides more information on this approach. The sensitivity of palliative care practitioners to the patient's psychosocial suffering and the philosophy underlying such care make the end-of-life context particularly conducive to collaboration between psychiatrists and other mental health care actors, working to give shape to an adapted care plan. The psychiatrist-consultant's liaison function called upon to work with such patients here takes on all its vital importance.

The psychiatrist acts:

- by allowing the teams to express their apprehensions and by legitimizing them;
- by fostering the introduction of proportionate safety measures, when relevant;
- by helping the team adopt a professional and empathic approach, for example, by getting to the roots of their apprehensions concerning violence and suicide in light of the data and the science, but even more so by focusing attention on the patient's strengths, by proposing methods for getting around their weaknesses and by revealing, within the limits of confidentiality and with the patient's consent, parts of their life story that are likely to elicit empathy;
- by demonstrating the communications skills required during joint visits;
- by guiding the next of kin in their trajectory with the patient for whom the psychiatric disorder will have given rise to a relational experience that is often coloured by anger, guilt, shame or powerlessness, and for whom the experience of the terminal physical disease is much closer to the narrative of "normal" human experience and will create an opportunity for recovery, resolution or reinvestment.

Severe psychiatric disorders are often a criterion for excluding patients from participating in palliative care research. It is thus necessary to use judgment by taking into account the patient's psychopharmacological history and the scientific data on

general palliative care. Particular attention has to be paid to drug interactions, while being aware that, with the exception of lithium and gabapentin, all psychotropic drugs undergo oxidative metabolism in the liver.

Certain physical symptoms can be influenced in their manifestations and in their intensity by the symptoms of psychiatric disorders. Several brain structures involved in the development of psychiatric symptoms are likewise involved with regard to pain, nausea and fatigue. The latter are not solely influenced by manifestations of a psychotic type, and the psychosis does not protect one from physical suffering. Psychiatric symptoms can also be influenced by the physical experience of the disease: the impulsiveness of a cluster B personality disorder can be increased by pain or by confusion, rather than just represent a psychological reaction to end-of-life stress.

Consumption of alcohol or drugs, whose effects prior to the disease might have remained scarcely present will become more problematic in the context of polymedication and physical vulnerability. This should not however be an obstacle to the relief of symptoms. The pharmacological follow-up will have to be more focused, and the distribution of medication sometimes on a daily basis. Co-analgesic drugs must be optimized and methadone considered.

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#### 5.3.4 Delirium<sup>11</sup>

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Several aspects of delirium are relevant in the context of terminal care, such as its mimicry. It affects the level of vigilance, that is at the very foundation of all brain functions, and it may appear in the form of thymic, perceptual or motor malfunctions, or as anxiety. It may thus take the form of depression, mania, or psychotic or anxiety disorders. Suicidal thoughts are not rare. The perception of pain may be disturbed. The assessment and history of the patient will reveal any cognitive impairments, as well as the subacute and fluctuating nature that the diagnosis establishes. It is estimated that delirium exists in 30% to 70% of the palliative care population. Numerous palliative care milieus have equipped themselves with tools for its systematic screening, detection and early treatment and care, which makes it easier to resolve the symptoms: one must however note that this is done in the kind of milieus, where the correction of etiologies other than those that are drug-related is however less easy to do.

Delirium is a frequent source of distress for the patient who experiences the symptoms and who has the feeling of losing control over their own thoughts. It is also disturbing for the family. At the very end-of-life, delirium is very often a part of the overall organ failure phase that leads to death. Further back from the end, Lawlor's study<sup>38</sup> estimates that 49% of the cases are reversible. Most of the time, multiple causes are at play. Amongst the etiologies upon which it is often possible to take action, one can point to psychotropic drugs, dehydration and hypercalcemia<sup>38-39</sup>. With regard to psychotropic drugs, Gaudreau<sup>40</sup> has observed that doses equal to 2 mg of lorazepam, 15 mg of corticosteroid and 90 mg of morphine were often associated with the onset of delirium. Bruera has observed that increases in doses by 30% within the previous three days

were frequently associated with the occurrence of a delirium from opiates. It is thought that the brain requires about one week to get used to the cognitive effects of such a change and to recover a clear sensorium. Infections, hypoxia and disseminated intravascular coagulation are more difficult to treat.

Non-pharmacological treatment consists of two parts. The first, psychoeducation, focuses upon teaching the patient, the next of kin and the personnel that the cause of the disorder does not come from a trauma or any psychological weakness, but rather has a somatic medical source and is sometimes reversible. Explaining the fluctuating nature of the disorder helps one to not see deterioration where in fact fluctuation is what is taking place. The second part deals with the patient's environment. One encourages the presence of the next of kin, of familiar objects in the room, as well as simple, repeated and clear communications that will re-orient the patient and announce each action that will be taken. The benefits and drawbacks of restraints have to be evaluated and discussed in such a way as to minimize their use, in that continuous surveillance by an orderly at the patient's bedside is preferable.

The pharmacological treatment is a symptomatic one. The decision is made on a case by case basis with the person and their next of kin. One has to take into account the potential for reversibility based upon the etiology and the phase of the terminal disease. One must also weigh the nature of the symptoms. Generally speaking, one treats agitated or anxious patients, or patients whose perceptual symptoms are excruciating. Those whose delirium is hypoactive and with soothing hallucinations can be treated with non-pharmacological measures alone. We know however that the hypoactive form can be activated at any time and that it responds just as favourably to medication, with a notable improvement of the MMSE<sup>41</sup>.

Haloperidol is often the drug of choice. The oral route is usable in most cases, but a subcutaneous injection is often used in palliative care. The intramuscular and intravenous routes are also available. The parenteral doses are equal to double the oral dose. Doses of 0.5 mg to 1 mg are repeated every 45 to 60 minutes until the target symptoms are under control. Seldom are more than 20 mg every 24 hours necessary<sup>42-43-44-45-46-47-48-49</sup>. Some treatments will add or alternate doses of 0.5 mg to 1 mg of lorazepam to the agitated patient. It should be noted that benzodiazepines can increase delirium<sup>50</sup>, unless it has been caused by a withdrawal from benzodiazepines or from alcohol. Methotrimeprazine (12.5 mg to 50 mg every 4 to 8 hours, maximum 320 mg per 24 hours) can be administered by the parenteral route (SC or IM). Analgesic adjuncts are regularly used in palliative care, but they can have a hypotensive effect, be very sedating, and anticholinergic. A growing amount of data indicates that risperidone (0.5 mg to 1 mg bid) and olanzapine (5 mg to 20 mg per day) are also effective. Less conclusive data is also available for quetiapine, aripiprazole and ziprasidone. Typical or atypical neuroleptics appear to increase cardiovascular mortality and mortality from infectious diseases of senior citizens with or without dementia<sup>51-52</sup>. This increased risk is considerable and might be dose-dependent. As paradoxical as this might appear in a context of end-of-life care, all this data remains important for the families and should be addressed<sup>53</sup>.

## 6. PALLIATIVE SEDATION

Practised for several years in the medical milieu, continuous palliative sedation has been formally legalized. Its goal is to relieve resistant symptoms by rendering the person unconscious. The prognosis is generally under 14 days<sup>5</sup>. It is thus a last resort method of care which can notably apply to vomiting, hyperactive delirium, pain, and respiratory distress. Notwithstanding popular belief, palliative sedation does not accelerate death.

The recourse to palliative sedation to treat psychological symptoms is far more controversial. Indeed, the literature is vague when it comes to defining this concept and assessing its use in clinical situations. The palliative care network in the Province of Quebec identifies four reasons why psychological distress differs from resistant physical symptoms<sup>54</sup>:

- It is difficult to define a resistant character when examining psychological distress.
- There exists a dynamic variability of these symptoms over time, depending upon a person's capacity to adapt and their resilience.
- There are fewer side effects from conventional treatments of psychological symptoms, compared to conventional treatments of physical pain.
- The presence of resistant psychological symptoms is not necessarily proportional to the degree that one's physiological deterioration has progressed, and would therefore be further removed from the anticipated moment of death.

However, recourse to intermittent palliative sedation for a few hours or a few days provides a way to relieve psychological symptoms, since a good number of patients will feel better after a period of prolonged sleep, even though the profound causal factors still remain present<sup>54</sup>.

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### Clinical vignette n° 2:

#### Palliative sedation and psychological symptoms

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Ms. J, 75 years old, is suffering from respiratory insufficiency after a long chronic obstructive pulmonary disease. She is oxygen-dependent and can no longer get around on her own. Her condition has been deteriorating progressively for a few weeks now, which leads her to speak to her doctor, in the presence of her three children, regarding her wish to not prolong the treatments and that one should let her go without any probing, should complications occur.

A week later, her breathing is increasingly difficult. Already, a few years ago, she had talked about being scared stiff by the thought of suffocating to death. At the last visit, she insisted upon the fact that she sensed that this was about to happen. Indeed, the personnel tells the doctor that she is very anxious and that sometimes, she hyperventilates, cries and screams to not let her die

by asphyxiation. The doctor prescribes regular doses of clonazepam, but since she already has benzodiazepines in her profile, the anxiolytic effect is rather disappointing from a clinical point of view.

The doses are increased progressively, until the doctor asks for a meeting with the patient and her children to discuss the next stages of care. During this meeting, Madam reiterates that she wants to have nature take her away and everyone agrees together to optimize the palliative care. The children revisit the subject of their mother's anxiety that is not responding satisfactorily to the medication being given. The doctor explains the risks and benefits of increasing the doses of benzodiazepines, notably on her state of consciousness and respiratory function, which Madam and her children fully and knowingly accept. As they hope that they could come visit their mother again and find her sufficiently lucid to engage in conversations from time to time, the doctor then proposes intermittent palliative sedation. Madam dies ten days later, surrounded by her next-of-kin and at peace.

This vignette demonstrates that in reality, the psychological symptoms of distress in the presence of a terminal disease might sometimes require a more intensive treatment: the latter will alter a person's state of consciousness, and potentially precipitate death. *But, although the suffering is poignant when the symptoms are at a peak, intermittent relief may make the end-of-life more acceptable for the patient and their family, because it can provide a way for there to be moments where the conversations will be exempt from severe symptoms.* The CMQ, along with the Société québécoise des médecins de soins palliatifs published a guide that might interest the reader, available at : <http://www.cmq.org/publications-pdf/p-1-2015-05-01-fr-la-sedation-palliative.pdf>.

## 7. MEDICAL AID IN DYING

### 7.1. Conditions for obtaining medical aid in dying (article 26)

The administration of medical aid in dying is a strictly regimented care process, circumscribed by the *Act respecting end-of-life care*. Accordingly, only a person who makes a request in a free and enlightened manner and, who meets all of the following conditions can ask for medical aid in dying:

The request for medical aid in dying is above all an expression of suffering whose relief does not inevitably mean that it will be done.

- Be an insured person within the meaning of the Health insurance act (chapter A-29).
- Be full of age and capable of giving consent to care.
- Be at the end of life.
- Suffer from a serious and incurable illness
- Be in an advanced state of irreversible decline in capability.
- Experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.

In the process, the request must come from the patient himself or herself and he or she must sign a form in the presence of a health care or social services professional. This request must be reiterated by the patient during interviews with their doctor. At any time, patients may withdraw their request or ask to postpone its administration. These parameters seek to limit the slippery slope so often evoked and dealt with in Appendix I.

We invite doctors to think about some of the elements that are related to these conditions:

- The request for medical aid in dying is above all an expression of suffering whose relief does not inevitably mean that it will be done. It is essential to understand the context in which the request for adequate relief is being made.
- Several destitute patients or patients with a mental illness don't renew their health insurance cards. This parameter exists so as to avoid medical tourism, but could deprive certain sick citizens from receiving terminal care.
- According to our understanding of the Law, the legislator wishes to avoid medical aid in dying vis-à-vis patients under protective supervision or covered by a mandate set out in the Law regarding incapacity and then officially certified. However, the jurisprudence confirms that a person who is incapable may be legally capable of consenting to specific forms of care.
- The end-of-life condition is not well defined in the Law. In several jurisdictions, end-of-life is defined by a prognosis of survival that is under six months. It is difficult to predict the evolution of a disease beyond six months in the majority of illnesses. The vagueness surrounding this definition thus leaves room for a doctor's interpretation. For some doctors, only the terminal phase is considered as a criterion for obtaining medical aid in dying. The CMQ published a practice guide on medical aid in dying and attempted thus steer doctors towards indices that suggest that a patient is unambiguously in an end-of-life situation (<http://www.cmq.org/publications-pdf/p-1-2015-09-10-fr-aide-medicale-a-mourir.pdf>). Although certain foreign jurisdictions sanction euthanasia for a prognosis of over six months, the spirit of the Quebec Law more strictly covers the end-of-life. This means that medical aid in dying and continuous palliative sedation should not apply to purely psychiatric conditions, without any medical condition, since the former are not associated with end-of-life in their natural evolution. Of course, patients with psychiatric illnesses are citizens like any others and will be able to take advantage of end-of-life care, when they suffer from serious and incurable physical diseases.
- With regard to constant and intolerable psychic suffering, we have referred to the controversy that exists in the palliative care milieu on its definition and how to respond to it, should it not be accompanied by physical suffering. In addition, even physical pain can be difficult to quantify objectively<sup>55</sup>. However, psychic suffering can obviously occur at the same time as physical symptoms and in a situation of advanced physiological deterioration. For example, we could think of untreatable vomiting, fecal vomiting, irreversible neurological symptoms such as paralysis or dysphagia and respiratory insufficiency. In other cases, psychic suffering occurs notwithstanding the acceptable control of physical suffering, for example, faced with a loss of autonomy or as death approaches. The Law requires suffering that cannot "be relieved in a manner that the patient deems tolerable." This introduces an aspect that is so subjective that it could make any

negotiation difficult when the doctor believes that other interventions could still be done. The doctor's professional judgment here remains essential: he or she has the best experience to propose treatment options to the patient commensurate with their suffering. He or she must thus explore them adequately with the patient before responding favourably or not to a request for medical aid in dying. For now, in the absence of adequate medical literature, the Law requires doctors to find creative solutions to discuss with the patient when the constant and unbearable character of suffering does not give rise to a consensus. That said, it should be recognized that the doctor can never fully grasp the totality of the patient's experience and that only the latter can describe what they're really feeling and going through.

The doctor's professional judgment here remains essential: he or she has the best experience to propose treatment options to the patient commensurate with their suffering.

In view of such complexity, we encourage the teams to examine together, and then with the patient and their next of kin, the nature of the disconnect between what they can observe and the experience that the patient is going through and describing to them. A psychotherapeutic approach, existential or spiritual, for example, could help the patient navigate through their psychic suffering, which is always potentially reversible.

Chochinov's thoughts are also interesting on this subject<sup>8</sup>.

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## 7.2 The doctor's obligations (Article 29)

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Before providing medical aid in dying, the doctor must:

1. be of the opinion that the patient meets all the criteria of section 26, after, among other things,
  - a. making sure that the request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure;
  - b. making sure that the request is an informed one, in particular by informing the patient of the prognosis for the illness 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 with the patient at reasonably spaced intervals given the 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 who they wished to contact;
3. obtain the opinion of a second physician confirming that the criteria set out in article 26 have been met.

The doctor who is consulted must be independent, both vis-à-vis the patient who is requesting medical aid in dying and vis-à-vis the doctor who is requesting the second opinion. The latter must take cognizance of the person's dossier and examine it. The doctor must express their opinion in writing.

We interpret the spirit of article 29 as being geared towards clarifying and ensuring the soundness of the patient's decision, by exploring its foundations, the sense of the course of action that is being taken, its durability in terms of time and its articulation vis-à-vis social bonds. It is very likely that doctors will encounter patients who present a request for medical aid in dying with various degrees of ambivalence: is this ambivalence linked to depression, to a personality disorder or other psychiatric disorder, to relational problems or perhaps even social pressure?

The concept of decision-making conflict elaborated by the Ottawa Decision Support Framework (ODSF), is enlightening in this regard<sup>56</sup>. "It is defined as an uncertainty with regard to the option to be favoured when decision-making will imply a choice amongst contradictory options regarding which there might potentially be associated certain risks, losses, regrets or that can be in contradiction to one's personal values<sup>57</sup>." The decision-making conflict arises from a combination of several elements<sup>58</sup>, including, for example:

- Insufficient knowledge of the clinical problem, the possible solutions and the reasoning that underlies them, as well as the risks and benefits;
- Unrealistic descriptions associated with the risks and benefits of the possible solutions;
- Personal values that are not clearly drawn, which may undermine the person's ranking of the relative weights to be given to the risks and benefits that are present;
- Normative perceptions that are hampered by what the person in question thinks to be the best choice, seen from the perspective of their next of kin;
- Untimely pressure by one's peers taking the form of persuasion, influence or coercion;
- Inadequate personal and (or) external resources for making a decision, including the support available from one's next of kin and the information being communicated by the health care professionals.

Although this model was not developed specifically for the medical aid in dying decision, it is relevant. Is this ambivalence linked to psychic suffering that deserves to be better defined? Here follows a list of questions that could stimulate a dialogue, inspired by an article by Gastmans<sup>59</sup> et al:

- What do you understand regarding your medical condition (diagnosis and prognosis) and the treatments that are being proposed?
- How do you see the upcoming battle against your disease?
- What are your expectations vis-à-vis the evolution of the disease and the treatments being proposed?
- What counts for you the most, since you have become ill or are dying?
- Is your next of kin aware of your medical condition and the treatments being proposed? How do they perceive all this?
- Do you feel that you're receiving adequate support in making decisions about your health? How do you think this could be improved?
- What palliative approaches that are available are you and your next of kin familiar with?
- Have you talked with others about your wish to die (or request for medical aid in dying)? How has that influenced you?

- Since when have you been thinking about this solution? Has your opinion on this subject evolved over time?
- What is motivating you to request medical aid in dying? What are the links between your medical condition, your personal situation and your request?
- Do you hope that some of your symptoms or difficulties could be relieved? Do you think that you could be accompanied in this end-of-your-life phase in a better fashion and if so, how? Would this make you more open to considering alternative solutions?
- Do you feel that certain mechanisms to better navigate through your end-of-life phase are not available to you in your hospital, or in your region?

It would be worthwhile to note the patient's reactions during such a dialogue. Although an open mind will be dependent upon each individual patient, a patient who would refuse to talk about their reasons could make the doctor consider that there are other issues and considerations involved, such as a psychiatric disease with suicidal thoughts, or a history of abuse, amongst other elements.

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### **Clinical vignette n° 3:** **The approach of death and its fluctuations**

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Hospitalized for a major depression 12 years ago at the age of 50, Mr. B was diagnosed with inoperable lung cancer. At the time, his depression had greatly improved and palliative radiotherapy was proposed. The patient was treated accordingly for three months and, six months later, an X-ray confirmed a substantial decrease in the size of the tumour, but the prognosis for survival was nonetheless only a few months.

Unexpectedly, several years go by, to the point that the radiology controls are sometimes up to 18 months apart. The patient almost forgets about his cancer, his children as well (they meanwhile lose their mother, and the patient's brother, to cancer), all the more so in that numerous vascular and metabolic conditions are at the forefront of their health concerns.

10 years after the diagnosis, the pulmonary cancer returns with a vengeance. The patient then knows that he will soon die and deals with this reality peacefully, reassuring his children, hoping to take advantage of the time left to read and spend time with his next of kin, without suffering: he goes into the palliative care unit where it seems that providing him relief is very difficult, without putting his consciousness into a state of limbo.

Accordingly, for a few weeks, his next of kin spend lots of time with him, as does his doctor who visits him, talks about what he's reading, while the team in the unit accompanies him through this final phase: he thus spends many moments enjoying total lucidity.

However, when he expresses his intimate feelings to his next of kin, he talks in a more banal fatherly fashion, which is surprising in view of what he projects and realizes since the diagnosis of a fatal relapse. The psychiatrist then questions him

gently about what he's feeling, on the manner in which he confronts the serious recurrence. Repeatedly, the patient talks about what he would like to do following the hospitalization, making many plans while his prognosis is only but a few days.

These totally unexpected moments make his children very uncomfortable, to the point of believing again in partial remission as was the case for so many years. Even the care team is a little taken aback as the patient's statements are so affirmative.

For the health care team, it is clear that the analgesics can not be the only cause involved: the patient is really between what he knows, what scares him, and what he hopes despite the unbearable pain he's enduring to be able to speak again to his children.

We can thus legitimately ask ourselves many questions about the process of integrating one's imminent death, when marked by such fluctuations. It goes without saying that the evolution of a disease is often filled with surprises that defy the gloomiest prognosis. If this man's awareness about his disease and its consequences were such a "teeter totter", and yet his thinking processes worked so perfectly, then would it not be possible that such a scenario could likewise occur for certain requests for medical aid in dying?

This vignette shows that the desire to die, as an acceptance of the inescapable does not remain fixed in certainty, as of the moment when it is formulated. Likewise, it illustrates the invaluable role of psychosocial care integrated into the end-of-life for a patient and their family, who were present right up until the very end: this support provides a way to refine the interventions in line with the physical and psychological condition of the patient whose death is approaching.

the desire to die, as an acceptance of the inescapable does not remain fixed in certainty, as of the moment when it is formulated.

Faced with such fluctuations, it takes very little to convince us that ensuring the free character of the patient's request is an important task for the doctor. Is the patient a victim of abuse (physical, psychological, financial, or sexual) or neglect? Despite all this, some patients put themselves into situations that might appear awkward, but they will however have chosen with full and complete discretion and with full knowledge of the situation, such as going into debt or bequeathing their assets to their more or less well-intentioned next of kin. In this specific case, it is not strictly speaking a situation of abuse, but it does risk becoming one.

#### **Sidebar 1:**

#### **Pitfalls to be avoided: experiences that could influence a patient's request for medical aid in dying**

- Abuse (physical, psychological, financial, or sexual) or neglect
- Inheritance or expiry of a life insurance policy
- Feeling of being a burden for one's next of kin
- Family pressure with regard to personal or religious values
- Perception of the patient's suffering by their peers

Patients indicate that they have not had enough time to talk about their medical condition with their doctor, or didn't quite know right away how to ask their questions and would like to once again get to the root of all the aspects that pertain to their care. The doctor must take the time necessary in an end-of-life situation, over several meetings, all the more so given that patients get tired more rapidly and that several symptoms may hinder their concentration and capacity to make decisions. They must therefore verify the patient's understanding and often reiterate their explanations. The work of the American internist, Angelo Volandes, is very interesting in this regard<sup>60</sup>. This caregiver encourages doctors to talk more with their patients about the planning of care.

**Side-bar 2 :**

**Clues that the consent was not free and enlightened<sup>61</sup>**

- The patient greatly underestimate their prognosis.
- They can only name a few treatment options and palliative care.
- They can not explain the risks and benefits of their choice or are not aware of important elements.
- They have other questions to ask the doctor about their condition and their choice.
- They express dissatisfaction with their doctor or treatment team.
- They fear not receiving care, or being discharged or punished if they refuse.
- They seem to be the victim of abuse by a third party.
- They show signs of cognitive disorders or pervasive psychiatric symptoms.
- A third party is so proactive that the patient has limited involvement in decisions.
- Some information is hidden from the patient.

The issue of the persistence of suffering is quite difficult to discern, since suffering is both an objective and subjective experience. It's imperative to listen to what the patient says about this matter so that one may discern if other issues which might appear to be intractable could be the subject of worthwhile interventions (pain that is poorly treated, untreated depression, family conflicts, etc.). Although the patient's guarded prognosis can give rise to a feeling of urgency to act, a space for conversation must be made available. In other jurisdictions, the request for medical aid in dying must be reiterated after a two-week interval, during which the dialogue continues to refine a shared understanding with the patient, their family and the different resources involved. This interval seems reasonable to us. Indeed, a study demonstrated that 50% of patients change their minds after 2-6 months<sup>62</sup>, while another study, by Chochinov, reveals, on the contrary, that the desire for death can be rather stable over time<sup>63</sup>.

As the Law suggests, discussing the patient's request and their medical condition with the members of the care team is imperative. Several objectives may thus be fulfilled:

- Evaluate the patient's trajectory and that of their next of kin faced with the end-of-life phase and adjust the interventions accordingly.
- Optimize the palliative care currently under way.

- Ensure the consistency of the patient's request.
- Address any worries about the reasons underlying and consistency of the request.
- Prepare the administration of the care in a personalized fashion.
- Assist the caregivers who experience difficulties faced with certain end-of-life situations.

With regard to interventions of a third party, we believe that it will practically always be necessary and will have to be explained to the patient. Indeed, information from a third party can provide considerable enlightenment that might change the diagnosis and the therapeutic interventions, particularly when psychiatric or cognitive symptoms are involved. The comparison is easy to do in terms of suicide risk, where communication with a third party often substantially modifies the grading of the severity of such a risk and the subsequent actions to be taken. This is also the case in the assessment of a patient's incapacity to consent to care. Abuse is often discovered in this way. From then on, even the evaluation of the free character of the patient's request could be skewed in the absence of contact with a third party.

Let's also mention the ultimate brutal consequences of an unannounced death of a patient upon their next of kin who would only learn about it as a result of being solicited as executors of their will or from a third party, or after being worried that they hadn't heard anything from the person in question. Let's note the deleterious effects upon the next of kin, such as the increased risk of suicide amongst children of someone who commits suicide.<sup>64</sup> To what extent can there be logically acceptable reasons to not inform one's next of kin of a request for medical aid in dying? Would the secret not be concealing elements regarding interpersonal dynamics that would deserve to be dealt with, both for the patient and for the future mourners? That said, the doctor has the duty to protect the confidentiality of their patient, and if the former wishes to speak to a third party, they must agree with the patient on what can be shared. Faced with an absolute refusal from the patient that their next of kin be contacted, the doctor may conclude that their assessment cannot be completed and is not valid. Seeing as palliative care also covers the care provided to mourners, the team could use such an argument with the patient and open the discussion in this way to deal with the deadlock.

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#### **Clinical vignette n° 4:** **The input of a third party**

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Mr. D, a part-time university student, was 24 when admitted to the hospital for a delirium secondary to end-stage kidney failure. Indeed, he did not present to a hemodialysis session earlier in the week and on the morning of his next session, his brother found him in a shabby condition in his apartment. After resuming hemodialysis, Mr. D recovers quickly but has a completely closed attitude to the team. He then asks his nephrologist to stop the hemodialysis he has been receiving for five years now. He is evasive about his reasons and often ends the interview by remaining silent. A week later, he notifies his doctor he wants to receive medical aid in dying because hemodialysis sessions, the diet and the medication that he has to take it generating unbearable psychic suffering for him.

He adds that a fast end by way of an injection would be more dignified in his opinion than the progressive deterioration that is coming from stopping the hemodialysis. Worried about his patient's psychic condition, the nephrologist requests a psychiatry consultation to evaluate his patient.

The psychiatrist meets Mr. D a few times. Indeed, the connection is difficult with the latter, who is quite upset to be met by the psychiatrist, since everything was going very well before the hemodialysis was resumed. The psychiatric questionnaire is negative and the mental examination demonstrates nothing particular, other than the patient's secretiveness. Mr. D has good periods, when he is surrounded by his next of kin, he eats well and sleeps well. He truly understands his disease and the therapeutic options available. The psychiatrist mentions to him that the regular care team is very surprised by this shift in attitude, because six months earlier, he had contemplated a kidney transplant with the hope of resuming his full-time studies at school. Mr. D remains silent, and the psychiatrist informs him that he will communicate with his brother to obtain more clinical information, while still respecting the confidentiality of his situation.

The meeting with the brother confirms to the psychiatrist that the patient was not suffering from anxiety, affective or psychotic symptoms. However, he learns that for the past two years, Mr. D had begun to play poker on the Internet, which gave rise to big debts, which came on top of his loans and bursaries. Mr. D had to borrow money from his next of kin and the gambling problems don't appear to have improved over the last few months, on the contrary.

The next day, the psychiatrist reports this information to Mr. D. The latter breaks down in tears: he is ashamed and admits that he has almost not been eating for the past few weeks seeing as his finances are in such poor shape. The psychiatrist reformulates the problem with the patient: Mr. D. wishes to terminate his days faced with the debt that he judges insurmountable and to avoid humiliation vis-à-vis the people he loves.

We can clearly see that certain patient requests, as is the case here with the request for medical aid in dying, mask an unanticipated underlying problem. This smoke-screen request, difficult to uncover in the absence of a third party, must be dealt with by providing adequate support that will help identify solutions.

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### 7.3 Role of doctors and institutional decision-making bodies

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Seeing as several doctors are implicated when a request for medical aid in dying is made, it is worthwhile to adequately characterize and demarcate the role of each physician. The first is the one to whom the patient initially submits their request for medical aid in dying. The former is also the one who, where applicable, will often perform the act after considering all the options with the patient. This doctor will often be the patient's attending physician for quite a while. Seeing as a therapeutic relationship has been developed, it makes a dialogue easier, as well as the evaluation of the conditions required by article 26.

In the case where the doctor is not the attending physician, the doctor will be able to speak with the patient's family doctor and any other doctors who are involved. Doctors who do not have the intention of providing medical aid in dying will have to notify their patients and refer them elsewhere in accordance with the Law.

The second doctor who gets involved also has the responsibility to verify whether the patient meets the conditions set out in article 26. At all times, this doctor may propose alternative solutions. The latter doctor must be independent, in other words, not have any sustained

The consultant in question is also responsible for their decision on the medical and legal aspects, and must be able to justify them.

therapeutic relationship with the patient, nor links with the patient's family or the first doctor. The second doctor must meet with the patient in person: a telephone conversation is insufficient. Article 29 specifies that this doctor "must consult the patient's record".

It is sometimes necessary to get a specialist involved for specific diagnostic, prognostic or therapeutic questions. We recommend that this consultant be a third doctor, since the specialist is not always authorized to recommend alternative solutions in terms of palliative care, pain treatment or other non-specific medical conditions, nor to evaluate the prognosis in terms of end-of-life.

Article 29 stipulates the obligations of the attending physician and the independent doctor who gives a second opinion. The consultant in question is also responsible for their decision on the medical and legal aspects, and must be able to justify them.

We have seen earlier that the psychiatrist plays an active role in palliative care: more and more teams will see to establishing a regular collaboration. One often calls upon the latter in the event of doubts about the patient's capacity to ask for medical aid in dying, although doctors all have the skills to do such an evaluation. Certain requests will be made in the context of psychiatric or psychosocial problems. An offer of better adapted care may then be put forward as an alternative to medical aid in dying, sometimes leading to the withdrawal of the request. The identification of a disorder that affects the patient's capacity may also lead to a refusal. The experience of euthanasia in Belgium teaches us that depression is one of the most common reasons. Other retrospective publications, notably on access to assisted suicide in Oregon, draw attention to the under identification of depression and anxiety disorders.

The psychiatrist should not be considered, per se, as an arbitrator, namely if the patients satisfy or not the criteria to obtain medical aid in dying.

Several publications reiterate the importance of not restricting the psychiatrist's role to that of being a decision-maker<sup>65-66</sup>. The European experience with euthanasia and a few publications by psychiatrists underline the importance of this task while still warning against resorting to systematic psychiatric evaluations. For more information on the debate regarding systematic evaluations in psychiatry, we refer you to some of the writings of Ganzini and McCormack<sup>67-68</sup>.

The psychiatrist should not be considered, per se, as an arbitrator of, namely if the patients satisfy or not the criteria to obtain medical aid in dying. The only person who can genuinely resolve this kind of matter is a judge, who cannot be asked to play such a role each and every time some doubt exists.

Of course, the psychiatrist may give their opinion – he or she will have moreover justified their opinion in their consultation - , but the decision belongs to the attending physician. It is conceivable that his or her conclusion is that there is doubt about the patient’s capacity and that time and additional evaluations would be necessary. If the psychiatry-liaison consultation is sometimes coupled with an expectation of an urgent response, we suggest caution and that respect be paid to all the parties in question, namely, the patient, their family, the care team and the doctors (attending physician and consultant).

The clinical ethical committee may be called upon to sustain the care team. However, its task is not to decide, but rather to shed light on the situation, which does not always guarantee an outcome that will be a solution that is shared between the treating team and the patient. In this case, it would be viable to have the courts hear the matter. This specific case has obviously not yet occurred, but since death is what is at stake, all kinds of mechanisms are required in order to make the best decision.

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## 7.4 Capacity and incapacity

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According to article 4 of the Civil Code, *Every person is fully able to exercise his civil rights*. It is thus essential to understand that the capacity being recognized at the outset in the Law cannot be evaluated. Only incapacity can be submitted to a clinical evaluation and, if necessary, to a legal process.

Although there exists no legal definition of capacity, the geriatric psychiatrist Paule Hottin and the jurist and doctor Suzanne Philips-Nootens propose a clinical definition:

*“Capacity (still called mental ability) is the psychic condition, which can be assessed on a clinical level, that enables a person to carry out a specific task, at a precise moment in time, being able to think it through, analyze it and understand its implications, as well as the consequences of their decision.”*<sup>69</sup>

They also underline that “the legislator does not specify the criteria along which one must evaluate a person’s incapacity to consent to the care required by their medical condition.”

In her teaching endeavours, Dr. Hottin insists: to make sure that one respects the person's autonomy all the while protecting the individual, the evaluation of incapacity has to be targeted, customized and adapted in order to determine the appropriate protective measures.

to make sure that one respects the person's autonomy all the while protecting the individual, the evaluation of incapacity has to be targeted, customized and adapted in order to determine the appropriate protective measures.

The evaluation of clinical incapacity is not always an explicit process. A detailed evaluation can be contemplated only when a situation raises doubts about the capacity of the person in question. Doctors have all the skills needed to evaluate incapacity to consent to care. In practice however, only special cases should be referred to a psychiatrist, in which case, the attending physician must explain why they are requesting such assistance. But what should be the approach to the evaluation of incapacity in terms of requesting medical aid in dying?

We believe that an evaluation of incapacity to request medical aid in dying implies a global psychiatric evaluation, the evaluation of the incapacity to consent to this specific form of care (and to others, if applicable, for example to palliative care) and the dangerousness regarding the person themselves<sup>70</sup>. In addition, a psychiatric consultation coinciding with end-of-life care implies a diagnostic evaluation. Should the doctor suspect a more general incapacity, they can formulate an opinion related to the capacity to take care of themselves and to administer their property. Since the incapacity to consent to care is particular to each kind of care, the incapacity to request medical aid in dying would not mean as such that the patient is incapable of consenting to other kinds of care, or to taking care of themselves and administering their property, and vice-versa.

It should be noted that our jurisdiction is the only one where medical aid in dying is considered as care. In the field, doctors often refer to criteria as set out in Nova Scotia to determine a patient's incapacity to consent to care. However, the approach cannot be summarized to a few questions strictly linked to these criteria or even to others, that we are only taking into consideration for illustrative purposes.

In the Civil Code of Quebec, two articles are of particular interest to us:

*Art. 10: Every person is inviolable and is entitled to the integrity of his person. Except in cases provided for by law, no one may interfere with his person without his free and enlightened consent.*

*Art. 11: No one may be made to undergo care of any nature, whether for examination, specimen taking, removal of tissue, treatment or any other act, except with his consent. Except as otherwise provided by law, the consent is subject to no other formal requirement and may be withdrawn at any time, even verbally. If the person concerned is incapable of giving or refusing his consent to care and has not drawn up advance medical directives under the Act respecting end-of-life care (chapter S-32.0001) by which he expresses such consent or refusal,, a person authorized by law or by a protection mandate may do so in his place.*

Let's note right away that the *Act respecting end-of-life care* stipulates that the patient must be capable when they formulate a request for medical aid in dying, which excludes the possibility of resorting to a substitute providing said consent.

Advance medical directives that are part of a mandate given in anticipation of incapacity (or in the provincial register, once it is created) can likewise no more apply for medical aid in dying vis-à-vis a person who is incapable of consenting to such care.

a psychiatric consultation coinciding with end-of-life care implies a diagnostic evaluation.

The doctor who proposes the care must be the one who evaluates the patient's incapacity to consent to it, since they are the one who has provided the prior explanations to the patient,

in other words their diagnosis, prognosis and possible treatment options. The terms used must be adapted to the patient; one must ensure that the patient understands them and responds to all the questions. The most frequent and most serious side effects are amongst the elements of information to be communicated to the patient. This means that the doctor who receives the request and who is considering granting it, explains all the alternative solutions to medical aid in dying and explains to the patient how death will take place, including the situations, reported to him or based on their own experience, where things might not have gone well.

The American psychiatrist Paul S. Appelbaum<sup>71</sup> devoted a major part of his work to a patient's consent to care and to incapacity. He puts forward four skills that pertain to consent to care:

1. the ability to express a choice (communicate an unchanging choice);
2. the ability to understand information (diagnosis, prognosis, risks and benefits of treating and not treating, communicated by the doctor);
3. the ability to appreciate information on a personal level (self-criticism regarding the disease and the consequences of the treatment options on the person);
4. the ability to think through the information (weigh the pros and cons in a logical fashion, and that can be made explicit to a third party).

The Nova Scotia criteria (inspired by the Nova Scotia Hospital Act and the Canadian Psychiatric Association) are set out as follows<sup>69</sup>:

1. Does the person understand that they are sick and do they realize the nature of their disease for which a treatment is being proposed to them?
2. Does the person understand the nature and the goal of the treatment, based upon the information that has been provided to them?
3. Does the person understand the benefits and risks of the proposed treatment?
4. Does the person understand the risks and consequences of not undergoing the treatment?
5. Is the person's capacity to make a decision affected by their disease?

The Act respecting end-of-life care stipulates that the patient must be capable when they formulate a request for medical aid in dying, which excludes the possibility of resorting to a substitute providing said consent.

Appelbaum introduces the notion of the capacity to express a choice and personalizes these criteria, although the nuance is subtle. In any event, it is important that the doctor makes sure with the person "verifying the persistence of suffering and that the wish to obtain medical aid in dying remains unchanged, by talking with the patient at reasonably spaced intervals given the progress of the patient's condition."<sup>71</sup>

The stability of these criteria over time is thus crucial; it implies a significant amount of time being devoted to dialogue between doctor and patient. None of us have had the experience of providing medical aid in dying and we are drafting these thoughts before the Law actually comes into effect. We thus submit to you certain characteristics that distinguish medical aid in dying from other types of care:

- In medical aid in dying, death is the result that one induces, which is not the case for any other kind of medical care. For doctors who are used to preventing death at any price, the patient would have to provide the doctor with conclusive and convincing arguments to persuade the doctor that such care is justified.
- This kind of care involves a major emotional burden since it will lead to mourning. Although in the media, several families of ill patients who pass away say that they are relieved by the death of their loved one and have deplored that they didn't have access to medical aid in dying, the reality could be significantly different. Indeed, this publicized information concerns families who are involved in the terminal disease process and who appear to be unanimous regarding the trajectory towards death, which is far from being the case for all patients.

Finally, this involves a kind of care that is regimented by a specific law that compels institutions to offer it. The institution's obligation to find a doctor to perform the act for the patient who so requests it could put pressure upon the doctor who is ambivalent with regard to the patient's capacity. It's very unusual in a health care setting that care must be offered at any price. In a context where doctors are not very numerous or overworked, where there are waiting lists and stays in emergency rooms that go on and on, referring the case to another colleague after having conducted a long investigation could be a difficult task on both an organizational and collegial level.

We also explained above that an evaluation of the dangerousness could be part of the evaluation of the person's incapacity to request medical aid in dying. Indeed, it is entirely possible that a request be formulated by a patient, as a way to give shape to suicidal thoughts that are independent of their medical condition. An exploration of their reasons could reveal that the suffering at the very heart of their request is associated with a psychiatric disorder, such as depression or a psychotic disorder. If the patient's request is refused, are they then planning to move on to committing suicide? It should be underlined that the expression of a wish to die amongst patients who are in the terminal phase of a disease is more frequent in the case of psychiatric disorders<sup>72</sup>. It is also on a case by case basis that doctors will be able to express a valid opinion to determine whether suicidal thoughts are involved, which are linked to a treatable psychiatric pathology, or whether the wish to die is being expressed within the limits of the normality that can be expected when someone is confronted with a terminal medical condition.

This therefore means that the evaluation of a patient's incapacity to request medical aid in dying will have to be personalized and conducted in an ambience of widespread collaboration geared towards the patient's well-being. In any event, with time and experience, it will be important for the doctors in question to examine and contemplate anew the criteria of incapacity, in such a way as to protect the most vulnerable of patients.

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### **Clinical vignette n° 5:** **Severe psychiatric disorders and incapacity**

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Mr. R, 50, has a diagnosis of schizophrenia with very severe functional impairment and notably often speaks in a jargon.  
A decade ago, he had a paranoid and agitated relapse after he stopped taking clozapine, which, however, had kept him well stabilized for several years. While hospitalized, he refused to resume clozapine for a long time, partly because of the necessary blood tests, and partly for reasons that will never be elucidated.  
Several years later, a new severe psychotic decompensation brought him back to the hospital, where it is found that most of the medications indicated no longer work or are not tolerated, and the patient suffers greatly. The question of clozapine therefore arises again: several interviews are conducted to explore whether the patient can understand his situation, what he thinks of clozapine and its constraints, why the doctor, with whom he has an excellent relationship, proposed this medication.

Through his inimitable speech, it will become clear that the patient's consent is informed (his memories of the drug are accurate and he accepts blood samples despite concerns) and free (it will be entrusted to the senior resident to assess whether the patient agrees to it for himself or especially due to his "friendship" to the doctor). This astonishing term in this context will particularly highlight what follows.

The medication quickly brings a beginning of improvement but leukopenia settles and worsens with total disappearance of neutrophils despite discontinuation of the product. This then creates confusion in the health care team, both for the imminent danger posed and the need for daily blood tests.

A radical change occurs in the man who becomes the best support for the caregivers by enhancing his usually very restricted speech, and being very tolerant to all the constraints required by his haematological status.

Finally, he shows continued evidence, during this period, of his precise understanding of the crisis, leaving no doubt about the quality of his consent to care.

This story shows to what extent free and enlightened consent may exist for someone with a mental illness, as severe as it might be. It also illustrates some avenues to pursue in order to adapt an evaluation of a patient's capacity to consent to care when the terrain is difficult, notably by multiplying the number of sessions and by working as a team.

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### **7.5 Key elements of the psychiatry consultation in the context of a request for medical aid in dying**

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Now that stage has been set, we can more specifically address how the psychiatric evaluation of a patient who requests medical aid in dying could be conducted. As for any request for a consultation, one must first have the doctor making the request specify the reasons for the consultation and their expectations. It is particularly important in the case of a request for an evaluation whose ultimate conclusion could lead to a person's death. The irreversible character of this decision calls for a clinical process that is thoroughly fleshed out. Also, the requesting doctor should provide details to the psychiatrist concerning the medical condition, the prognosis, the treatments attempted and offered, as well as the evolution of the request for medical aid in dying, over time. A discussion in person, or over the telephone, with the requesting doctor is often desirable to properly prepare for the evaluation of the patient.

The consultation should have much in common with the psychiatry-liaison evaluation, in that information is gathered on the patient's social situation, the personal and family psychiatric and medical background, the patient's current and previous medications, allergies, lifestyle, and an evaluation of the psychiatric symptoms with the patient and collateral information from next of kin sources. If the request for consultation pertains to an evaluation of the person's incapacity to ask for medical aid in dying, a diagnostic evaluation is incontrovertible.

With regard to the method, we believe that an evaluation in an end-of-life care context, let alone in the case of a request for medical aid in dying, must include at least two meetings, with an interval to be defined depending upon the prognosis and the particular situation of each patient. Indeed, patients are often very ill and get tired easily. Meanwhile, the literature has rather little to say about the evolution of one's wishes for death over time. It is thus prudent, as the Law so stipulates, to ensure that the request is reiterated. The patient's clinical condition should likewise be as stable as possible, and whatever elements or conditions that could be reversible will have been treated, and all the elements that drive the patient to request medical aid in dying will have been dealt with. The psychiatrist must take time to reflect upon the situation before rendering their opinion. The latter should convey their opinion to the patient, the patient's family or other important third parties, if the patient accepts to do this, as well as to the caregiver team to make sure that everyone receives the same information. The discussions that follow will guide the patient and the treatment team towards the next stages of treatment and care, namely, the delivery of medical aid in dying, or the pursuit of new avenues that would lead to a solution.

Now, we draw your attention to the following elements that are worth exploring with patients who are in an end-of-life situation.

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### **7.5.1 Family situation**

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Psychiatrists deal regularly with bereavement situations with patients and are very familiar with the deleterious impact of losing a loved one. It is thus worthwhile to evaluate the patient's social network, harmonious and difficult relations, and whether the decisions related to end-of-life care have been discussed with a person's social reference groups and peers. Having the responsibility of dependants will strongly influence the experience of dying. The request for medical aid in dying may also be the expression of a desire to remove oneself from a family conflict. In other situations, it can be the reiterated expression of long-term dissatisfaction, exclusion from one's network or one of its parties. Indeed, there is no limit to the wealth and diversity of the end-of-life cosmos.

We also believe that death is the opportunity for patients to leave a legacy to their next of kin. They may indeed share some of their property, deal with their will and discuss with their next of kin what has really mattered in their life. Sometimes, the patient will also wish to settle certain disputes with their next of kin in order to die in peace. In the book "Dignity Therapy" by Chochinov, he describes a very interesting method for end-of-life patients (primarily those suffering oncological diseases) to leave a generativity document to their next of kin, in other words, a personalized look back on the life they have lived.

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### **7.5.2 Psychiatric history**

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The psychiatric history can put us onto the right track regarding the patient's contemporary active psychopathology. A complete diagnostic evaluation is however no less necessary. Not any previous psychiatric disorder constitutes an absolute contraindication to medical aid in dying.

Under all circumstances, although this requires more time, active listening and reflection, patients with psychiatric disorders must have access to the same quality of end-of-life care.

The older a condition is, the less susceptible it is to affect the present moment, unless there is a relapse. The presence of a severe and persistent disorder will require an adaptation of the care provided. The identification of new disorders directly related to the experience of the physical disease and the end-of-life phase will add to the understanding of the patient's suffering.

It is important that patients with previous or active disorders have access to quality end-of-life care when they are suffering from a disease that will lead to their death. A multidisciplinary approach is important here to share, as a team, the weight of the difficult decisions that sometimes have to be made. It can be worthwhile for the professionals to ask one another

what kind of care they would offer to such and such a patient, if they were not suffering from a personality disorder, depression or other disorder in order to better determine what might be interfering with making a decision. A psychiatrist's participation is difficult to avoid, and when possible, we suggest referring directly to the attending psychiatrist, who is better informed about the patient's values, network and preferences, that have already been voiced regarding their health. Under all circumstances, although this requires more time, active listening and reflection, patients with psychiatric disorders must have access to the same quality of end-of-life care.

### 7.5.3 History of suicidal behaviour

It is obvious for psychiatrists, who are often called upon to care for suicidal patients, that receiving a request for medical aid in dying can evoke feelings of a dual allegiance. Can we be protecting life on the one hand, while on the other hand, participating in an authorization for death? What about the patient who has already endured suicidal thoughts, and the one who has already made one or several attempts? In such a context, it is impossible for us to draw a one size fits all guideline for how psychiatrists should be acting. One must approach this question candidly and frankly with the patient, and should there be the least bit of doubt, with a third party and one's colleagues. Time may also help one make a decision, by remembering that that a request for medical aid in dying must be reiterated, over a period that is not specified in the Law, and in this case, susceptible to being adapted to the particular context.

Previous suicidal thoughts would suggest psychopathology. This calls for a detailed evaluation of the patient's current psychiatric symptoms. An advanced phase of cancer, a poor prognosis, delirium, unrelieved pain, depression and despair are all factors that are associated with a higher risk of suicide<sup>73-74</sup>.

Several clinical situations prove to be genuine enigmas for care teams. Imagine the case of a patient who has made a request for medical aid in dying and who proves to be downright suicidal with a plan, and this, within the framework of an acute psychiatric disorder. This patient wants to sign a refusal of treatment, when access to medical aid in dying has been denied to them. What are the consequences of putting them under preventive confinement? Should the person be cared for in the psychiatric or palliative care unit?

Could a judge be asked to hear and decide the question of preventive confinement and the granting of medical aid in dying, all at the same time?

#### 7.5.4 Family background

The psychiatric history and history of suicidal behaviour in the patient’s family may lead to detecting a psychiatric disorder or draw attention to suffering that might have taken root in the family experience. It should be recalled that having already accompanied one’s loved ones through an end-of-life phase can be a major predictor of psychological distress for the same person who enters into a palliative phase. The history surrounding the death of one’s significant others is also rich in information. Indeed, the patient may have experienced the agony that a next of kin has gone through and fear going through the same thing, or may not have resolved their mourning for the deceased, amongst other things.

#### 7.5.5 Exploration of the medical condition and functioning

A good knowledge of a person’s medical situation will enable the psychiatrist to grasp the principal issues and challenges laid out by the attending physician. Since he or she is a doctor, the psychiatrist could respectfully ask for clarifications regarding any attempted approaches or those in progress. A clinical discussion might pave the way towards avenues to explore for solutions that are adapted to the patient. Thereafter, the psychiatrist can observe the patient’s trajectory in view of their medical condition, their understanding of the therapeutic challenges and issues, as well as the prognosis, and their experience.

The latter aspect is very important, since the patient doesn’t experience their disease owing to the symptoms alone. Often, physiopathological explanations don’t manage to soothe the patient. In point of fact, disease is associated with a very intimate experience that consists of psychological, existential and spiritual dimensions. Addressing them with the patient and providing the latter with space to talk about these things will often be beneficial. What are they experiencing that doesn’t make sense in the current state of affairs? What is at the very heart of their difficulties?

In his numerous works, Dr. Harvey Max Chochinov attempts to characterize and circumscribe the factors that sustain a sense of dignity at one’s end-of-life. He proposes a model on his Web site<sup>75</sup>.

**Table 3:  
The Dignity Model**

CATEGORY	THEMES AND SUB-THEMES
Illness-related concerns	<p><b>SYMPTOM DISTRESS</b></p> <ul style="list-style-type: none"> <li>• <b>Physical distress:</b> Pain, discomfort</li> <li>• <b>Psychological distress:</b> Medical uncertainty, anxiety</li> </ul>

CATEGORY	THEMES AND SUB-THEMES
	<p><b>LEVEL OF INDEPENDENCE</b></p> <ul style="list-style-type: none"> <li>• <b>Functional capacity:</b> Ability to perform normal daily tasks</li> <li>• <b>Cognitive acuity:</b> Ability to think clearly, to reason, to remember</li> </ul>
<p><b>The person’s perspectives and practices (The Dignity-Conserving Repertoire)</b></p>	<p><b>HOW THE PERSON PERCEIVES THE SITUATION</b></p> <ul style="list-style-type: none"> <li>• <b>Autonomy/control:</b> Do I feel in control?</li> <li>• <b>Acceptance:</b> Am I at peace with what is happening?</li> <li>• <b>Maintenance of pride:</b> Do I take pride in myself?</li> <li>• <b>Optimism:</b> Do I look forward to anything?</li> <li>• <b>Role preservation:</b> Have I lost my place in life?</li> <li>• <b>Continued sense of self:</b> Am I the same person I used to be?</li> <li>• <b>Resilience/fighting spirit:</b> Do I have the will to go on?</li> <li>• <b>Generativity/legacy:</b> What will I leave behind me?</li> </ul> <p><b>WHAT THE PERSON DOES TO EASE THE SITUATION</b></p> <ul style="list-style-type: none"> <li>• <b>Living in the moment:</b> Not dwelling on the medical concern</li> <li>• <b>Maintaining normalcy:</b> Sticking to a routine</li> <li>• <b>Seeking spiritual comfort:</b> Finding solace in spiritual or religious practices</li> </ul>
<p><b>Interactions with others (The Social Dignity Inventory)</b></p>	<ul style="list-style-type: none"> <li>• <b>Care tenor:</b> Being treated with respect and kindness</li> <li>• <b>Privacy boundaries:</b> Feeling control over privacy</li> <li>• <b>Social support:</b> Ability to draw support from friends and family</li> <li>• <b>Burden to others:</b> Worry about how others are affected</li> <li>• <b>Aftermath concerns:</b> Concerns about those left behind</li> </ul>

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## 7.5.6 Conceptualization of life and death

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It is worthwhile questioning the patient about their own personal experiences (or those of their social reference groups) with regard to death that have shaped their conception of the end-of-life. Religious and spiritual beliefs will also have a major impact when death is imminent and upon decisions regarding care. Discussing these subjects will help to properly support the patient with regard to their needs in these areas. One might try to have a spiritual counsellor or an interested member of the patient's religious community get involved, as well.

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## 7.5.7 Specific psychiatric disorders

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### 7.5.7.1 Depression

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Since depression is often associated with ideas of death, going from passive thoughts about death to an active plan to commit suicide, detecting these things is essential. Symptoms of depression, confusion and despair are three of the psychiatric symptoms that are most often associated with the desire for an early death. The frequency of depression and anxiety symptoms is also higher in this population (8% to 47%)<sup>76</sup>. On the other hand, faced with imminent death, would it be justified to undertake a treatment to overcome depression where the time required for it to possibly produce results would exceed the prognosis and refuse the patient's access to medical aid in dying on this basis? The answer is never simple.

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### Clinical vignette n° 6: The desire to die and to commit suicide

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Ms. Y, aged 60, has been married for 35 years and has one daughter. She is a retired official from the age of 59: "I wanted to do things differently from others, to enjoy life a bit before falling ill, we see so many who waited too long to retire and die within the following months. " At the time of the psychiatric consultation, she suffers from an ovarian neoplasia stage IV, that was diagnosed three months after her retirement. It is an aggressive disease that recurs 4 months after chemotherapy. Current treatment only leads to partial remission. She has no psychiatric history. Family background is heavy: two of her four siblings, and a niece were afflicted in the same year with oncological disease. Two are palliative and refused the extension of life treatments. She is referred due to discouragement following the relapse of her illness. Her distress is partially identified at screening (Distress screening Tool<sup>77</sup> = 6 and Edmonton Symptom Assessment Scale, depression sub-scale<sup>78</sup> = 7).

She suffers from suicidal thoughts “because Bill 52 is not yet in effect.” She expresses a long-standing belief that the end-of-life doesn’t make any sense, a belief that is influenced by the experience of her father's death in a CHSLD a few years ago, following a degenerative disease and a metastasized cancer.

Madam has looked into possible international options that might enable her to have access to assisted suicide and euthanasia, but would prefer dying surrounded by her loved ones in Quebec. The psychiatrist diagnoses a severe major depression. He also concludes that there is high risk of suicide, but that it is not imminent, since Madam is pondering suicide methods (a deliberate accident, poisoning) as an alternative to another plan, namely, going to Switzerland. She accepts however to receive psychiatric care and postpones her plans until later. The psychiatrist finally ascertains an autonomous personality, and that she is a woman who is focused on a caregiving role, with long-standing mistrust that stems from experiences of psychological and physical abuse where she had been both a witness and a victim in early adulthood.

After a few weeks, she shows some notable clinical improvement after some integrative psychotherapy based upon cognitive elements and focused on a search for meaning and a pharmacotherapy treatment consisting of a SSRI and an atypical neuroleptic. The psychiatrist watches as the risk of suicide disappears and she again begins to commit to certain projects, notably that of preparing photo albums and various souvenirs for her next of kin. She maintains her position regarding medical aid in dying, but specifies that: “When I’ll really feel that I’m deteriorating and when the treatments will be stopped”. Madam collaborates in the research protocol with the hope of prolonging her life and considers that her quality of life has improved.

However, a little bit later, she suffers a relapse of her depressive symptoms whose initial symptom will be the announcement to her psychiatrist that she feels that the time has now come to get things going. She plans a trip to Vermont, where medical aid in dying is now available for foreigners. She is however not suicidal. The completion of the chemotherapy treatments under way and an error in medication that was made in her pill dispenser appear to have been the triggers of this relapse.

After recovering from her depressive symptoms, she postpones her plan once again for later on and hopes to obtain medical aid in dying in her native land, rather than having to go abroad. The psychiatrist observes that the need for and sense of an imminent act to die is again significantly diminished. Dialogue however remains difficult: she sees that the medical community is opposed to her vision which often affects any exchange with her, but the follow-up is maintained.

This vignette underlines the importance of correctly detecting depressive symptoms and diagnosing depression with any patient who makes a request for medical aid in dying. Interestingly, we see here that her initial position with regard to medical aid in dying is not influenced by the depression but her feeling of urgency to put it into practice is.

even in the presence of an alliance that is difficult to consolidate, dialogue is always possible with the patient and their next of kin.

We observe that notwithstanding this position, she wants to prolong her life: the affirmation of her values is simultaneously given shape in her choice of treatments (participation in research to live longer and helping her family, helping other sick people by advancing science) and her interest in medical aid in dying (avoiding end-of-life suffering and the loss of autonomy that has already been observed). Even though the patient is convinced that end of life suffering is a dead end, she nonetheless maintains an

openness to care that may allow her to remain coherent with her vision of life and the end-of-life, notably with the purpose of remaining useful and controlling her suffering. Even when temporary, the relief provided may be sufficient and have meaning for a sick person, thereby modulating the expression of their choices, but also putting them into action. Finally, even in the presence of an alliance that is difficult to consolidate, dialogue is always possible with the patient and their next of kin<sup>79</sup>. The psychiatrist's communications skills and ability to build a real connection concerning sensitive subjects like distress, abuse, values and the human role, are just some of the additional tools that can help make this connection that is essential for being able to provide complete care.

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#### 7.5.7.2 Anxiety disorders

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For several patients, end-of-life and disease are linked to anxiety. Does it form part of an anxiety disorder whose treatment could be optimized, or is it a new phenomenon? What role does it play in the request for medical aid in dying? Let's underline that, *a fortiori*, when a patient suffers from anxiety, psychoeducation regarding the disease and its next stages will be greatly beneficial and can calm down the desire to die. That said, one must take the time, envisage several meetings, ensure that the patient properly understands what is said and that they are mentally receptive to receiving explanations.

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#### 7.5.7.3 Psychotic disorders

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The major challenge facing a patient with a psychotic disorder, who asks for medical aid in dying, is probably that of creating a therapeutic relationship and a dialogue, which are incontrovertible to determine whether delusional motives, for example, are at the foundation of their request. On the other hand, delusions and hallucinations are often sustained in schizophrenia, and if they are not linked to the request for medical aid in dying, their presence probably wouldn't alter the capacity to consent.

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#### 7.5.7.4 Delirium

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Outside of a major alteration of a person's state of consciousness, there are not any specific medical conditions that can be automatically associated with a patient's incapacity to consent to care. In this regard, delirium is no exception, since numerous patients who are totally coherent during the day will only deteriorate at night.

That said, some aspects of delirium could have an impact upon the capacity to consent to medical aid in dying. The difficulties in paying attention that are associated with delirium may make the patient confused in terms of understanding their medical condition, which often generates significant anxiety. The doctors will thus have to explain more often to such patients the nature of their condition and the treatment. For example, a patient could find their pain intolerable, since they do not realize that it fluctuates and they don't integrate the notion that the doses of medication are being increased as a way to provide appropriate relief.

On the other hand, some patients who suffer from delirium will talk about suicide. It is thus important to review with the family the background to the request for medical aid in dying. Giving precedence to a treatment targeting the cause of delirium in order to induce a remission would also provide a way to elucidate the patient's wishes with the patient himself or herself. The pain may be contributing to the delirium and generating dysphoria and the suicidal comments, which are reversible with an appropriate treatment. With a patient who has manifested their wish for medical aid in dying before the delirium, the Law would nonetheless require the patient to express their request and reiterate it and that their state of consciousness not be distorted to the point of rendering the person incapable. In the case of a delirium associated with the terminal phase of a disease, the relief of the symptoms would have to be targeted as a priority and the recourse to medical aid in dying would no longer be indispensable anyway.

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#### **7.5.7.5 Dementia and cognitive disorders**

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The thinking with regard to dementia is similar to that regarding delirium. Although dementia is a serious and incurable disease characterized by a cognitive deterioration that often evolves, the end-of-life that is linked to it often occurs at a moment in time where the patient has severe cognitive impairments, and is unable to move around or eat alone. It is difficult to imagine that such a patient could express a request for medical aid in dying and then reiterate it. That said, during the evolution of the disease, it is not uncommon that a patient develops another disease that could cause their death. In the case of a condition that meets the criteria to obtain medical aid in dying, the patient with dementia should not be excluded right off the bat, and an evaluation in due form should be conducted. The clinician would have to pay attention to the patient's understanding of their situation and to their capacity to maintain it over time. With this patient, *the fact that they would have already expressed their wishes to die faced with an incurable condition and intolerable suffering will be significant of course, but insufficient to provide medical aid in dying in the eyes of the Law.*

This would summon the psychiatrist to consider a cognitive evaluation screening or treatment. We would not recommend it however right away, since cognitive difficulties do not automatically mean an incapacity to consent to care. It would be more useful to see how these deficiencies affect the capacity to make decisions in the course of a complete evaluation. A test score is not a diagnosis and would thus not directly affect the decisions made by the doctor.

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## 7.6. The institution's obligations

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All health and social services institutions must offer end-of-life care, while palliative care hospices can determine those that they offer on their premises. Seeing as a person's consent must be free and not the result of outside pressure, regular palliative care must be available in a timely manner and of sufficient quality for all patients, so as to avoid having an institution's shortcomings leave a patient with no other choice than to request medical aid in dying. Several psychiatrists have told us that they are worried that financial pressures coming from an institution could eventually materialize if one considers all the pressure being put on the health care system to improve its productivity. Without even taking into account the ageing of the population, which will increase the number of patients who will need regular or a significant amount of care. It goes without saying that active care and palliative care must nonetheless remain available for all patients, regardless of the socio-economic context.

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## 7.7. Respect for one's personal beliefs

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In the Law, article 50 reads as follows: "A physician may refuse to administer medical aid in dying because of personal convictions, and a health professional may refuse to take part in administering it for the same reason.

Although it is imperative that psychiatrists be free to decide whether to participate or not in such care, a defection of psychiatrists could undermine the quality of end-of-life care.

In such a case, the physician or health professional must nevertheless ensure that continuity of care is provided to the patient, in accordance with their code of ethics and the patient's wishes. In addition, the physician must comply with the procedure established in section 31", which means "as soon as possible, notify the Executive Director of the institution or any other person designated by the Executive Director and forward the request form given to the physician." It is then the Executive Director of the institution who is responsible for quickly finding a doctor who accepts to deal with the request.

Psychiatrists must begin by thinking about their own personal involvement before formulating a conscientious objection. Whether it be for religious, ideological or other reasons, the psychiatrist could refuse to conduct an evaluation to avoid being linked to the act of providing medical aid in dying. This issue raises the whole question of professional identity, for example, of the psychiatrist who every day is trying to prevent suicide, or the doctor in palliative care who accompanies people who are dying until the very end. One should emphasize here the relevance of the work of Jacques Quintin<sup>80-81</sup> on the caregiver's ethical suffering, which was already poignant before the arrival of medical aid in dying. No doubt doctors will find themselves in difficult situations for all kinds of reasons and will have to find meaning through their own experiences<sup>82</sup>.

Even though it is imperative that psychiatrists be free to decide whether to participate or not in such care, a defection of psychiatrists could undermine the quality of end-of-life care. Indeed, the presence of an untreated or insufficiently treated psychiatric pathology is a factor to be considered faced with a request for medical aid in dying.

As is the case in the clinical situation of suicidal patient who has no other goal than his fatal plan, a request for medical aid in dying may be a smokescreen concealing another disease, such as a psychiatric disorder or agonizing psychosocial situation. It is thus eminently desirable that psychiatrists who refuse medical aid in dying do not automatically exclude themselves from the evaluation process, because their sensitivity will be able to improve the offer of care, while still opening a space for dialogue for adapting to the disease and to the end-of-life. For example, some psychiatrists will be available to evaluate end-of-life patients in pursuit of diagnostic and therapeutic objectives, but will refuse to get involved in the evaluation of incapacity to request medical aid in dying.

Notwithstanding the fact that the Law specifies that the patient ask the doctor for medical aid in dying, modern medicine upholds the notion that the decision be shared between doctor and patient. If the paternalistic approach is supposedly consigned to the history books, one must be careful to not swing over to the other extreme of the continuum, in which a patient asks for care that the doctor simply performs as requested. The doctor, the patient, the family and the system that they all are part of, can work out a common understanding and care plan by engaging in a dialogue in which everyone takes part, with their experience and their own personal issues.

Finally, several psychiatrists have expressed their concern about the whole ethical question of remunerating the act of medical aid in dying, or for any care that is related to this act. It is conceivable that some psychiatrists would refuse a specific payment, although the foregoing has not yet been spelled out in the Régie de l'assurance-maladie du Québec billing manual.

## 8. ADVANCE MEDICAL DIRECTIVES

When advance medical directives respect the terms and conditions stipulated in the Law, they have the same value as a desire expressed by a person qualified to consent to care, even though the person has become incapable. We still don't know when the advance medical directive register will be effective. In any event, all doctors should regularly discuss these questions with their patients. Indeed, a dignified end-of-life is facilitated by an early dialogue on the goals of

a dignified end-of-life is facilitated by an early dialogue on the goals of care and respect for the patient's decisions.

care and respect for the patient's decisions.

Interestingly, it was recently proposed to make use of video clips to help patients understand the procedure to which they were consenting, notably, with regard to intubation and cardiopulmonary resuscitation<sup>83</sup>. The Ottawa Decision Support Framework (ODSF) team has also proposed certain tools, such as the Ottawa Personal Decision Guide<sup>84</sup>, also available for the family<sup>85</sup>.

## 9. SUPPORT FOR DOCTORS AND CAREGIVERS

As doctors, even though we regularly encounter and deal with death, we are confronted with the suffering of others and our own mortality. Doctors and psychiatrists that could be called upon to make a decision must be able to enjoy support from their colleagues. One should recall that psychiatrists can contact the AMPQ if they want to discuss problematic situations they are encountering for which preventive actions could be undertaken and the Quebec Physicians Health Program (QHPH) to obtain support.

It is also just as important that the health care professionals in question can likewise receive the support necessary from within their own team but also, if needed, from the employee assistance program, or any other appropriate resources.

## 10. TEACHING

As this document so testifies, know-how-to-be and know-how are both essential in medicine. As end-of-life care becomes more accessible, relevant teaching must be given to all medical students and residents. In a situation where opinions are polarized, it will be necessary to treat the beliefs, values and choices of younger colleagues with respect. Accordingly, it will be necessary to avoid having physicians become proponents of one or another of the schools of thought, even more so than compelling them to perform acts that are contrary to their sentiments, within the framework of a hierarchical relationship. Clearly, this means being careful to not put residents, without any support, into thorny ethical situations.

It will likewise be necessary to determine at what point during a medical student's training would it be optimal to expose them to medical aid in dying, since the responsibility for practising medical aid in dying falls upon doctors. The CMQ recommends that residents do not perform acts of medical aid in dying, which would appear to be self-evident. However, this elicits controversy<sup>86-87</sup>. The training of students and residents will certainly have to be modified to deal with these new issues and challenges. The Faculties of Medicine are currently studying these questions to build up skills in end-of-life care and in the early planning of care. They must however meet the very same challenges as all of us, namely, to prepare themselves to do the work even before the CMQ and MSSS guidelines in this regard are available. We will thus have to keep a very close eye on this dossier.

Continuing education will also have to be offered to doctors who are already practising and this, in sufficient quantity and quality, so as to develop their skills in palliative care. They will thus be in a position to provide quality care and alternative solutions that are adapted to patients, before consenting to requests for medical aid in dying.

## 11. RESEARCH

As we will not be going backwards with regard to continuous palliative sedation and medical aid in dying, it will be important to study these practices to avoid the slippery slope and to ensure quality care. The Commission on end-of-life care, that will notably have the task of monitoring the application of the specific requirements pertaining to medical aid in dying, will have the duty to document and share the evolution of this experience with all health care professionals. There must therefore be opportunities created to better understand and document the psychiatrist's role and the psychological suffering that arises in this process. In this regard, we recommend that a psychosocial professional researcher sit on said Commission. We are also counting upon the fact that the Law would have the consequence, if not the goal, to improve research on end-of-life care in general, so that doctors can better assist patients in the final chapter of their lives, including its psychological, existential and spiritual dimensions.

## 12. CONCLUSION

The only certainty in life is death, we should all welcome the fact that special attention has been paid to end-of-life care over the past few years. We sincerely wish that this would pave the way for palliative care teams to grow in terms of numbers and skills. It is obvious that the *Act respecting end-of-life care*, notwithstanding its intentions to facilitate the work of doctors, raises a great many questions. Although it does establish a framework, it does not perform the acts in our place and it is not designed to manage the end-of-life in all its complexity. We have shared with you some of our thoughts, as well as the obstacles to be on the lookout for and certain avenues that might provide solutions. We hope that this document helps each one of us to gauge what medical aid in dying represents, and the circumscribed place that it should occupy in terminal care. We hope that we will all continue with the work at hand and contribute to the evolution of our society for the sake of all our fellow citizens.

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## NECESSITY TO CONTINUE AN ETHICAL REFLECTION ON THE SUBJECT

### Can the Law respond to all the individual and societal questions?

As health care professionals and notwithstanding recent legislative decisions, we must ask ourselves many questions about the future impact of our decisions on end-of-life care. In other words, the Law must not prevent us from thinking and reflecting, and not having professionals reduced to simple performers. The end-of-life is a situation marked by vulnerability: we must therefore avoid doing things that would lead people to think that their life doesn't have any value any more, or is no longer useful. Although autonomy is a central value of modern societies, the patient who would like to have different conditions of care could then not dare affirm his choice in front of their next of kin and the surrounding health care professionals. Accordingly therefore, if medical aid in dying were to become widely accepted and palliative care was not deployed adequately, a patient who would wish to continue living, despite the suffering, might feel constrained to ask, or to have a third party who is authorized to ask, to put an end to their life. The fact that Quebec and Canada have chosen to decriminalize medical aid in dying should not put an end to our thinking on this subject. Only Western societies have legislated on assisted suicide or euthanasia: do other cultures have solutions to suggest to us? Is this an unexpected consequence or better yet, innovative result of neo-liberalism?

### Medical aid in dying: combining euthanasia and care?

It is not surprising that the term medical aid in dying has been chosen: a euphemism to talk about euthanasia, some people would claim. Reactions, however, have been even stronger, pursuant to the decision to designate this act as care. For its detractors, the intention of killing is simply incompatible with the very notion of care. As there exists no incontrovertible proof that the normal use of appropriate and effective doses of pain relievers, which can relieve the sick person, cut short "the time remaining" in an end-of-life situation, medical aid in dying cannot be assimilated to other types of palliative care for this reason alone. The fact that it is administered by a doctor likewise no more justifies that it be described as care. As Aristotle said, there is no worse sophism than the sophism of words. Assimilating medical aid in dying to care is likely to have consequences: for example, faced with an incurable cancer, and in the course of accompanying the patient as they deteriorate and with the approaching mourning phase, one could envisage professionals offering medical aid in dying as a response – as a form of care.

### Dignity and quality of life

The argument of the quality of life has been advanced on several occasions by the defenders of medical aid in dying. But, the data is eminently subjective. How does one reach a consensus on a patient's quality of life without intrinsically judging its value?

Does this mean that there exist clinical situations in which any patient should cut short their days? The question of dying in dignity has insidiously become synonymous with medical aid in dying, while research on dignity in palliative care has been flourishing for several years now, without seeking to provoke death. Does there not exist some form of collective dignity, not any less valid, which would accompany the sick person until death without having this intention: the question of dignity appears to arise when a situation disrupts the person's trajectory placing an obstacle in their path that, this time, is manifestly perceived as intolerable. How does medical aid in dying provide answers to addressing this obstacle and working on it?

In every psychiatrist's practice, several times every day, each suicidal patient will undergo comparable radical experiences against which the practitioner will fight back: reference to the preceding has been made repeatedly above.

### **Continuation of treatment and relentless therapeutic interventions**

It is also possible to interpret a certain popular attachment in favour of medical aid in dying as a reaction to several problems that characterize the Canadian and Quebec health care systems. For example, according to a Canadian Medical Association survey, 4 out of 5 patients are not confident that they will have access to the health care their medical condition will require when they're older<sup>88</sup>. One might suggest, in view of this certainty, alarming for politicians and professionals alike, that it might appear more reasonable to solicit medical aid in dying. Meanwhile, the progress of medicine has given rise to a wide assortment of therapies, and for some patients, the invasive treatments used at an older age are a dreaded option. It would be a shame that the population would perceive medical aid in dying as the only means for avoiding relentless therapeutic interventions. Indeed, the cessation of care is a right that has been recognized for a long time, for which work must be done so that the patient is not alone in making this decision.

### **The sacred principle of autonomy**

Autonomy has been placed at the very heart of the medical aid in dying debate. In our society, people want to be able to decide for themselves what will happen to them. That said, one mustn't forget that autonomy is one value amongst others. As John Keown underlines, killing someone against their will respects the value of the killer's autonomy, but greatly harms that of the victim and that of society<sup>89</sup>. The uniqueness, here, is that this autonomy is exercised with the inevitable participation of the doctor: right off the bat, medical aid in dying is heteronomous, that is dependent upon somebody else. If truth be told, the individual is in constant interaction with others in their life: at work, their family, their activities as citizens, in the services that they receive from the State. This autonomy thus appears to us as somewhat illusory, since "choices do not arise out of the simple desire of individuals: they are the product of values that originate in interactions with others and the influence of institutions and systems that surround us."<sup>90</sup>

This is therefore one more reason to encourage the patient to talk about what is motivating them to request medical aid in dying: this interaction with others, even though it appears to be alien to their desire to make decisions for themselves alone, can open up the patients outlook and help the person specify what they're going through. Boudreau and Somerville add that respect for a patient's autonomy could culminate in detrimental consequences, such as undermining the fundamental values of our society regarding the nature of medicine and law<sup>91</sup>.

### Medical aid in dying and unassisted suicide

On February 6, 2015, the nine judges of the Supreme Court of Canada ruled unanimously in the Carter decision to remove the prohibition against medical aid in dying (euthanasia and assisted suicide), independent of the end-of-life phase. For decades now, all psychiatrists fight to treat the suicidal thoughts of a considerable number of patients by trying to help them find meaning in their lives. They therefore ardently hope that this decision, as well as the arrival of legislation that authorizes medical aid in dying in the Province of Quebec, will not give rise to a slackening of health care professionals' efforts to prevent suicide: especially to the extent, one must recall, where euthanasia and assisted suicide have already been practised with patients suffering from depression (in accordance with other legislation), and that the end-of-life is no longer a criterion to circumscribe these requests. Also, one is surprised to read in the Carter decision that the option of suicide (without medical assistance), in the presence of intolerable suffering, is considered to be the primary solution: in the judgment, one can indeed read that "The right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly. Here, the prohibition deprives some individuals of life, as it has the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable."<sup>92</sup>

Our experience has taught us that suicide is a symptom that one must explore with the patient, and that provides a way to open up on experiences that have barely or not at all been brought to light beforehand. When the patient exposes their reasons, the psychiatrist takes note, and their exteriority then enables them to contemplate other solutions with the patient.

By offering all palliative care services to people, it will enable a majority of patients to find peace. The sole decriminalization of medical aid in dying will not attain the goal of diminishing the suicidal thoughts of end-of-life patients. One must thus be careful that our public policy statements doesn't end up normalizing suicide. The concern is all the more significant in that the rate of suicide (without medical assistance) in Oregon has increased more rapidly than the American average, ever since the legalization of assisted suicide, attaining a rate that was 49% higher in 2013<sup>93</sup>. Although the causal link cannot be formally established, one must remain vigilant: *Suicide is an act that can be prevented and regarding which society does have a responsibility.*

## The slippery slope

The experience of other countries where assisted suicide or euthanasia are practised have witnessed well documented abuse. Involuntary euthanasia cases have been recorded<sup>94</sup>, without counting the fact that the total number of patients who die in this way increases from year to year and reached 4.6% of the deaths recorded in 2013 in Flanders, in Belgium<sup>94</sup>. In Oregon, death by assisted suicide increased by 44% between 2013 and 2014<sup>95</sup> and by 15% in Holland, between 2012 and 2013<sup>96</sup>.

Let's point out, amongst other cases, that of a patient with tinnitus<sup>97</sup>, of a patient who underwent an unsatisfactory gender reassignment, of an anorexic patient who after lodging a complaint against their psychiatrist and others, suffering from a depression, obtained an assisted suicide or euthanasia. A study in the Lancet indicated that 23% of all deaths by euthanasia were not reported in Holland in 2010, compared to 20% in 2005<sup>98</sup>. Another study suggests that 34% of Dutch doctors would favourably consider euthanasia for someone with a mental illness, dementia or even someone who said they were tired of living<sup>99</sup>. In Belgium, from 50 to 60 psychiatric patients died via euthanasia in 2013-2014, namely 2-3% of the people who were euthanized<sup>100</sup>. Moreover Mr. Distelmans, the President of the Belgian Federal Commission on Euthanasia, explained in an interview that he feels that bipolar patients are eligible for euthanasia. He is not, alas, the only person who thinks like this<sup>101</sup>.

In contrast to the Quebec law that is yet to come into effect, the Carter decision does not stipulate an end-of-life situation as a criterion to obtain medical aid in dying. It also decriminalizes assisted suicide. One could probably expect that Quebecers will ask for assisted suicide or euthanasia, regardless of their prognosis. And if they were to come up against a refusal, these requests could make use, in Court, of the legal weight of the Carter decision.

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