Brief for the Commission on Dying with Dignity
July 16th 2010-07-13

Identification of Authors:

We are nurses with many years of experience working in Quebec hospitals. We work in various fields, notably in pain control and critical care.

Summary:

Nurses have more first-hand experience with dying people than any other group of healthcare professionals. Much progress has been made and continues to be made in the areas of pain control and palliative care medicine. We help patients die naturally in dignity everyday. We question why NOW should the question of euthanasia and physician assisted suicide be discussed particularly when there is so much more to offer dying patients in terms of pain control, comfort care, psychosocial and spiritual support. We should in reality focus on the issue of accessibility to quality end of life care by well educated professionals consistently across the province. We, nurses, would like to be part of hospitals that are committed to focusing on and improving in providing quality end-of-life care. We do not want our profession to be associated in any way with the termination of our patients' lives. We are pleased to have a forum to express why it would be unacceptable to pass a law that makes euthanasia and/or physician assisted suicide a medical act essentially decriminalizing it for the following specific reasons:

1. There is a growing distrust of healthcare workers and disdain for hospitals in Quebec, largely because of negative experiences. If we start euthanizing patients this growing disdain will worsen. We hear stories of the Dutch and Belgian people fearing to go to the hospital when they need to because they don't want to be killed. We want our hospitals to be seen as places of healing. We want our profession to be seen as a healing profession. We, as nurses, do not want to be associated with any type of killing.

2. The mission of nurses is to provide compassionate, professional, quality, evidenced-based nursing care that helps patients achieve an optimal level of health and when this is not possible, as in the case of terminal illness, to support them and help them adapt to the losses associated with their condition. Cutting short the process of dying by killing patients will interfere with our role in helping the patient and family adapt to the loss. Dying is a process and in every stage there is a lesson for the patient, family and healthcare workers to understand and accept what is happening. The struggle to alleviate suffering and succeeding in making the suffering person comfortable and at peace is a process in which the best characteristics of the patient, healthcare team and the patient's entourage to surface. This unleashing of love allows all the parties involved to open up and to become the best versions of themselves. This unleashing leads the patient to "die healed".

To remove a stage of dying by euthanizing a person means that both the patient and his or her entourage is deprived of the opportunity to come to terms with a difficult situation, to resolve any issues left neglected throughout a person's life and to become better healthcare workers and people. Euthanasia tragically results in reducing the chance that the patient dies in dignity which in turn makes the grieving process for those left behind more difficult and lengthy.

Each experience in life helps one to grow. The same must apply in the experience of dying because not only does the patient and his entourage, but also the healthcare professionals involved learn and grow as human beings.

3. More attention must be paid to the provision and improvement of quality pain control and palliative care consistently across the province. Healthcare workers need more education. Pain control teams need to be established in all hospitals. More funding is needed for palliative care centres with affiliations to hospitals. The Montreal General Hospital provides an excellent example of how palliative care patients' needs are met through various teams dedicated to these types of patients and the collaboration between these teams.

4. Considerable confusion exists amongst the general public surrounding end-of-life care treatments. Often pain control is understood as being euthanasia and commonly we see patients and family who are wary when offered appropriate comfort and pain control. The introduction of euthanasia and/or physician assisted suicide as another "treatment option" will make end-of-life care even more confusing and difficult for us as Nurses to provide good care to our patients.

5. Allowing euthanasia in hospitals opens the door to many other dangerous practices. This includes experimental treatments on terminally ill patients on the grounds that 'they are going to die any way' as well as euthanizing sick but not terminally ill or chronically ill patients. Nurses will be asked to administer these life ending drugs. This practice occurs in Belgium (see reference 1.). Even if these examples are not legalized many physicians will feel more justified in carrying out euthanasia in such cases and will request that nurses to participate if euthanizing for terminally ill people becomes legal.

General Presentation:

1. Our main reason for preparing this brief is our desire to protect our image as nurses. Caring for the sick is our daily work. We do not want to be identified as those people who can collaborate with doctors to give the lethal shots that kill. The image threatens our professional identity and the manner in which we want to continue to be perceived by the public as caring empathetic, compassionate, trustworthy, well-educated, competent professionals.

It is crucial that our patients can trust us in order for us to carry out our work effectively. We care for patients of many different races and creeds. However, caring is universal

and is our key to establishing a trusting relationship with our patients. There is a climate of suspicion of healthcare workers in Quebec and this has started to spread to the profession of nursing. Nurses always have had a very good public image and having nurses participate in any way in the killing of patients will only jeopardize this image.

The following is an example of how caring for the physical needs of dying patients builds trust which has a consequence of promoting an environment of well being for the patient and family even in the context of end of life:

One of the undersigned nurses was assigned to a “difficult” patient with a “difficult” family. Most staff members did not want to care for this patient. The patient came from a different culture from that of the nurses concerned. When the nurse entered the room the first morning she was assigned to the patient, she found the family were apathetic as if they were waiting around for the patient to die. The room was messy, the lunch and dinner trays from the previous day were still full of food. The room smelt not only stale but also of the old food. The patient was unclean, it was especially notable that his mouth mucous membranes were dry and crusted over, and he had bad halitosis. He could not speak.

The nurse cleaned the patient’s mouth, put Vaseline on his lips and a sponge with a cup of ice water to freshen his mouth as needed. With this simple intervention the patient was able to speak!! She cleaned up the room, opened the door and window. The family and patient came back to life! They began to ask appropriate questions, used the call bell to make appropriate requests and returned in the afternoon with a CD player and music that the patient, a music lover, enjoyed.

The nurse discovered that the family felt they were not understood and that there wishes were not being respected, they felt that they were forced to resign themselves to the fact that their loved one was dying and there was nothing to be done. They were scared because they did not understand what was happening, they did not know what to do and were not offered any information. They resented this and retaliated by making unreasonable requests. The nurse resolved this situation by demonstrating caring. She gave the patient’s dignity back to him by cleaning him and his environment and helped the family understand that they had an important role, not to save the patient from dying but to accompany him. Although she could not spend hours with the patient, the time she spent she used well to demonstrate that she cared, wanted, and she knew how to help and that above all she respected the patient. She earned the trust of the patient and family.

2. Dying is a process that we as nurses have assisted patients with for centuries. Nurses take pride in their ability to accompany dying patients and their families through the stages of dying. It takes years for a nurse to develop her expertise in meeting the needs of the dying patient. Nurses accompany so many people through difficult illnesses they have a pivotal and key role in the process. They are experts, not only in a scientific manner but also in an intuitive way because of their cumulative exposure over time.

Dying patients who are surrounded by their loved-ones in conjunction with a supportive, well educated and caring healthcare team have the most dignified deaths. The time that they have from the moment they decide to stop fighting for a cure to the moment that they die is a very special time in not only in their lives but also in the lives of their loved ones, their colleagues and even their acquaintances. It is a time for them to go over their lives in their minds and make right any perceived wrongs. Many feel grateful that they have this time rather than to have died a sudden death. They have a chance to review their lives, settle their affairs and spend tender last moments with their loved ones.

Dying patients who die alone, in pain, unclean, in busy hospital wards or the emergency room, are unable to die dignified deaths. Unfortunately this happens often. Patients and their families are not given the opportunity to embrace the stages of dying and to “die healed” because they are too busy trying to get the appropriate attention. They unfortunately feel neglected and inhuman.

It is unacceptable to allow people to die this manner in our society in the twenty first century. But the answer to counteracting this is not euthanasia or physician assisted suicide. This is only a ‘cop-out’ solution because politicians are essentially saying to the general public: ”We cannot afford to give you the care you will need when you are dying, so we will help you to die or we will help you to kill yourself.”

The experience of dying is one of life’s most intense experiences for the person, of course, but also for his entourage. It is likely that almost every second, every moment of this intense time is permanently imprinted in everyone’s conscience. Every kind word and gesture as well as every insensitive remark or rough hand remains strong in the memory of the many people involved as well as in the memory of the dying person. Unfortunately too many people in Quebec have had very unpleasant experiences. This is due to the poorly trained professionals and support staff, the lack of resources, and even an apathetic attitude possibly stemming from a poorly developed philosophy on life and death.

The time period prior to dying to review one’s life is a process that is provoked by the stages of dying. It includes suffering. Suffering occurs in many different forms and pain is not the worst form of suffering. The struggle to help the suffering person enables the dying person and his entourage to reach an intimacy, a unity and a tenderness that no other life experience can offer.

The following is an example to illustrate this. One of the undersigned nurse was assigned to care for a dying woman and helped the patient to accept help from her husband and helped the husband to perform some of the physical care for his wife.

The husband spent everyday at the bedside of his wife, usually reading or watching TV. They appeared to be a loving couple but did not converse much. The patient started to become depressed and understandably the husband followed suite. When the nurse

arrived she perceived that the husband felt useless. The patient confided to the nurse that she felt she was a burden to her husband and she felt that he should not feel obliged to come in everyday. The nurse decided to ask the husband if he would help with little tasks in the room by starting with removing her meal tray. From this small task she gradually taught the husband to do most of his wife's physical care. He eagerly learned to do everything that was required to care for her physically and began to ask more questions about his wife's condition. The moods of the couple improved to the point that they seemed to be glowing. When the nurse commented to them on their cheery moods the husband told her that by helping his wife in the manner that the nurse had taught him that he felt more in love with her than he had been when they were young and healthy. He felt finally satisfied that he had fulfilled the promise that he had made to her years ago when they married.

3. We know that in many cases in Quebec's hospitals as the situation described above rarely occurs because the staff are not trained to pick up on end of life issues. Why? The appropriate resources do not exist so patients and their families fall through the cracks. Legalizing euthanasia will not contribute to improving this situation. We who work in pain control and with complex palliative care patients are aware that there are many interventions and combinations of interventions which by virtue of a multidisciplinary approach that are very effective for complex pain and palliative care cases. We know this because we have been well trained, we have the resources in place and we help patients die peacefully and in dignity on a daily basis. A patient who asks for euthanasia is a defeat for us.

It is a defeat for a Nurse and our society to start euthanizing our patients. It would cause many working in the caring professions to leave either to find more satisfying work or, perhaps more likely, because of burnout. When a patient dies, no matter what the circumstances, it is always a moment to reflect since this event touches us profoundly as human beings. When a patient dies naturally after we have worked hard to help them through their last moments, it is momentous. But after some reflection we can move on. However, when a patient dies because of either a medical error or some kind of neglect by the treating team this results in profound and lengthy suffering which may lead to burnout and leaving the profession. This is the effect that euthanasia will have on the healthcare professionals involved and required to carrying out such a process.

We work very hard to protect life and this includes protecting our patient's dignity at the end of life by ensuring that they get the care they need to be at peace and to be physically comfortable. It is part of human nature to find solutions to problems. The fields of palliative care and pain management have progressed because we, as Nurses, are always looking for solutions to every unique problem. It has led us to expand our knowledge and open up our creativity.

The suffering that occurs at the end of life is seldom from physical pain alone. Pain is complex and multi-faceted, whether it be at the end of life, acute or chronic. The quest to alleviate suffering is central to human nature and what we in the "caring professions" have made it our professional mission.

In chronic pain, many patients are suicidal but most do not kill themselves. They are in reality asking for the help they need to find a solution and to cope with the pain. They are on a quest and they make it their life's main goal that to stop their suffering. One patient who suffered from chronic pain who although he had been through many treatments to alleviate his pain, declared to his doctor, after his wife had passed away, that if the doctor had nothing more to offer him in the way of treatment, that he had decided that since he had been accepting the pain for his wife. So, now that she was gone, he would kill himself. The treating doctor, saddened on hearing this information, brought up this issue in the multi-disciplinary rounds in his clinic. The chronic pain team was stunned. Nobody could offer a solution, except the psychologist who said that no important decisions should be made so soon after losing a loved one. The meeting ended on a very sad note. We were defeated. The treating doctor (a chronic pain specialist) thought he knew every available treatment but was provoked by this patient's declaration. He used his phone to call other pain specialists around the world. He found a suitable treatment for this patient. Although it was more than a week after the patient's suicide declaration, he phoned the patient to find him at home alive and he found that the patient readily accepted the treatment he offered. The mood at the next multi-disciplinary meeting was one of elation when the doctor recounted his quest and success in not only finding a treatment for this patient but in preventing his suicide.

4. The fourth reason why we as nurses do not want euthanasia to be decriminalized and performed in the hospitals we work in is because considerable confusion already exists regarding the goal of end of life treatments. Patients and families are confused not only between curative and palliative treatments but also as to the goal of comfort treatments: whether they are only to reduce pain, agitation, dyspnea etc or only to hasten death or both. Many family members leave the hospital after a loved one has died feeling guilty thinking that the treating team killed their loved one. The problem is that the families did not understand and were not given the clear information they needed. Some people harbor feelings of guilt for the rest of their lives because of such misunderstandings. Even healthcare workers are often not clear about the indications of pain medication at the end of life and terminal sedation. Healthcare workers are continually being educated on medicating patients appropriately for pain. The attitude of many physicians and nurses is that they do not want to be held responsible for causing the death of patients because of the pain medications they either prescribe or administer. Consequently they either under-medicate the patient or don't medicate them at all.

Imagine the confusion if euthanasia is introduced as another "treatment" option. Confusion will increase and in many cases the treatment of pain will be suboptimal. Patients will hesitate to ask for treatment and possibly even to seek out treatment for fear of being euthanized. Healthcare workers will be more hesitant to either treat pain or conversely be less attentive to the strict regulations surrounding the use of controlled drugs and give them more freely because it is deemed 'okay' if a terminal patient dies prematurely. Providing a drug whose indication is to end the patient's life will be made as simple as a nurse giving Tylenol but the only difference is that the physician will be giving it.

5. Finally, allowing euthanasia to be performed in hospitals as a medical act will give license to many other unacceptable practices to become acceptable. If euthanasia is allowable in the case a dying person who has uncontrollable suffering the question will exist for some- why shouldn't this practice be done for a psychiatric patient who also is suffering uncontrollably, but not dying. It is likely that treating teams will either make allowances for chronic patients or allow experimental treatments to be carried out on dying patients on the grounds that these individuals 'are going to die anyway'. We know many rules are frequently bent by well-intentioned healthcare workers and the consequences and results are often very negative. Physicians will feel justified to "bend the rules" for cases that are similar to whatever the law allows.

Similarly, nurses are regularly asked by physicians to perform interventions which are legally beyond the scope of their practice. It is inevitable that nurses will be asked to administer life ending drugs. We do not want to be put in this position. (see reference 1.)

We hope that we have demonstrated clearly that euthanasia is not a solution and it definitely cannot be seen as a medical act.

Allowing euthanasia will lead healthcare workers to have a false notion that we always have the answer. The answer can't be, if there is no other obvious one, that we will kill you. We, the undersigned, want to protect our freedom to say to the patient "We don't have a cure, but I can still offer you my skill and expertise to accompany you, help you and care for you and your family until the natural end of your life. I will help you and you will help me to grow as a professional and in my expertise and I can pass that on to another patient and his family."

The process of dying cannot be left to the individual because it is a necessary process that affects the life of not only the individual concerned but the lives his entourage and society in general and it requires accompaniment.

References:

1. Ingelbrecht, E., Bilson, J., Mortier, F., Deliens, L., The role of nurses in physician assisted deaths in Belgium, CMAJ 2010 182(9): 905-910

Signed:

Cristina Benetti, N, Operating Room, Jewish General Hospital (cribenetti@hotmail.com)

Mary Grace Griffin, BScN, Nurse Clinician-Pain Management Programs, Montreal General Hospital (marygrace7@hotmail.com)

With the full agreement and contributions of the following nurses:

Krista Brecht, MScN, Clinical Nurse Specialist-Pain Programs, Montreal General Hospital (krista.brecht@muhc.mcgill.ca)

Anita Cormier, N retired geriatric nurse, Quebec City (anita.cormier@videotron.ca)

Lise Dolbec, BScN, Innomar Strategies Inc., Rimouski (momzini@hotmail.com)

Julien Leduc, N. Neurosrgery, Hopital Notre-Dame de Montreal (gsboy2002@hotmail.com)

Sharon Mooney, BScN, MA, Nurse Professional Development Educator-medicine, Montreal General Hospital (sharon.mooney@muhc.mcgill.ca)

Anita Mountjoy, MScN, retired nurse manager and palliative care volunteer, Montreal General Hospital (anitamj51@hotmail.com)

Claire Nehme, MScN, Clinical Nurse Specialist-Pain Programs, Montreal Neurological Institute (claire.nehme@muhc.mcgill.ca)

Sharon Smith, BScN, Assistant Nurse Manager-ICU, Montreal General Hospital (sharon.smith@muhc.mcgill.ca)

Colleen Stone, BScN, Nurse Manager-ICU, Montreal General Hospital (colleen.stone@muhc.mcgill.ca)

Marianne Toledo, BScN, pediatric nurse, Montreal Children's Hospital (mtoledo@sympatico.ca)