



# **PALLIATIVE CARE...** CARING FOR LIFE



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“THE GOOD  
THAT ONE  
HUMAN BEING  
CAN DO FOR  
ANOTHER IS  
INCREDIBLE.”

- **Johanne de Montigny**,  
psychologist specialized in palliative  
care

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All too often associated only with death, misunderstood and sometimes forgotten, palliative care is not available as much as it should be in the Quebec healthcare network. But with the ageing population, the passage of *An Act respecting end-of-life care* which came out of the work of the Dying with dignity committee, its presence in public discourse is more marked than ever.

Encompassing pain management, symptom control, psychosocial and logistical support, palliative care focuses on life and the quality of life of patients as well as their loved ones. This is an invaluable resource to which not all Quebecers have equal access at the right time because it's frequently offered too late.

The palliative care orientation, which all the countries in the Organisation for Economic Co-operation and Development (OECD) have taken, is becoming important as more and more experts and studies confirm the efficiency of this type of care. Not only does it reduce healthcare costs, but when administered early, can even prolong life! Through short narratives and figures, this document presents an overview of the benefits of palliative care and the limitations of a system that isn't always able to administer it at the right place at the right time.



“I quickly discovered that palliative care isn’t limited to the last few weeks of life. Some patients are with us for months, even a year or more. So, we must help them live with the disease. Palliative care firstly involves accompanying patients through all the symptoms and stages of their disease. Sleep, nutrition, pain, degenerative effects, psychological changes, organizational adaptation, calming the situation, offering support, keeping relatives informed, etc. are all a part of palliative care,” says a nurse who provides palliative home care.

To understand the hurdles to the development of this care and identify needs, resources, and best practices, a team from the Canadian Cancer Society – Quebec Division (CCS) conducted nearly 50 interviews in various institutions (hospitals, CHSLD long-term care homes, CLSC community clinics, specialized organizations, and palliative care hospices). Palliative care general practitioners, hematologists, specialized nurses and psychologists, managers, analysts, volunteers, and family caregivers shared their experiences and vision.

**Everywhere, we see the same dedication, the same commitment and the same conviction.** However, resources, like the experiences of patients and their loved ones, are very uneven. Depending on their postal code, the healthcare institution’s organizational culture in the area where they live and the will or openness of doctors to the palliative care approach, Quebecers don’t all have the same access to palliative care and don’t all benefit from the same basket of services. Is access to palliative care akin to playing the lottery on the postal code?

## Palliative care... a human solidarity pact

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening disease:

- through prevention and relief of suffering by means of early identification and correct assessment;
- through the treatment of pain and other problems, whether physical, psychological or spiritual.”

This definition of palliative care (WHO, 2002) specifies that it must be administered by a multidisciplinary team and as early as possible during the disease, the course of which it can sometimes positively influence. The goal: enable patients to live the remaining days of their lives in the best way possible.

## What the figures say

### Cancer and palliative care

The Canadian Cancer Society estimates that 48,700 new cancer cases were diagnosed in 2013 in Quebec and 20,200 people, that is 55 per day, died of cancer. We estimate that 80% of patients who receive palliative care are those living with cancer (Shang 2013).

In 2011-2012, according to hospital statistics, only 8,200 people living with cancer who died in hospital, or 63.5%, received palliative care. This means that this care was not administered to more than a third of people living with cancer who died in hospital. A situation that causes concern to specialists in the field and for which patients and their caregivers are paying the price. Cancer-related pain is a real public health problem both for its frequency, estimated at 50% during the course of the disease and at 75 and 80% in the terminal stage, as its intensity. However, drugs, medical techniques and advances in palliative care knowledge make pain relief possible for the vast majority of patients.

## Access to palliative care beyond cancer

Despite the statistics that speak volumes and the 2004 adoption of a Quebec policy on end-of-life care, the deployment of palliative care in Quebec is still not up to speed.

According to the professionals interviewed, a highly variable percentage of Quebecers – that is between 20 and 60% depending on the region – have access to this care, which is uneven in type and quality. For the whole of Canada, the Canadian Hospice Palliative Care Association (CHPCA) states that: “Currently in Canada, only 16 to 30% of people receive end-of-life care, which for many is inadequate and given too late.”

Where home care is concerned, in 2011-2012, 20,565 people, with all kinds of diagnoses, received palliative care at home, which was a 6% increase in users since 2007-2008 (AQESSS, 2013). The need for the service and the number of users will continue to rise considerably during the next decade.



## An international scientific consensus: effective and profitable care

Nevertheless, the effectiveness of palliative care as well as the expertise and the approach that it requires are scientifically recognized. In different parts of the world, studies conducted by experts of all stripes, including eminent oncologists and specialists, validate not only the merits of this care, but also its efficacy and cost effectiveness.

In August 2010, the highly respected *New England Journal of Medicine* (NEJM) published the results of a research conducted by a thoracic oncology research team led by Dr Jennifer S. Temel at the General Hospital of Massachusetts on the early introduction of palliative care among 151 non-small cell metastatic lung cancer patients. The conclusions are impressive:

“Patients in the cohort who received specialized palliative care from the time the metastasis was diagnosed were less depressed, underwent fewer strong treatments (that is, chemotherapy) at the end of life, enjoyed a better quality of life and lived at least two to three months longer than patients who had received general medical or acute care.”

The Temel study confirmed the opinion and research of a number of other experts. Its results were picked up widely by the scientific community and embraced by a few oncologists, but not all. A scientific consensus on the relevance and importance of introducing palliative care for patients with terminal cancer has since been reached. At the end of 2013, the NEJM published a second article (Parikh, Kirch, Smith & Temel) recognizing the effectiveness of this care: “When it is introduced at the earliest possible, specialized palliative care enhances the quality of life, reduces medical costs, enables more informed and judicious choices to be made concerning treatments for patients living with cancer at an advanced stage.”

Many studies pertaining to the question of cost arrive at similar conclusions:

- palliative care introduced at the beginning of the terminal stage can on average reduce the total healthcare cost by 33% (Brumley et al., 2007);
- among hospitalized patients, palliative interventions reduce the cost by U.S. \$2,500 per admission (Morrison et al., 2008);
- savings of \$7,000 to 8,000 per patient (Morrison et al., 2008);
- when palliative care is administered by a specialized team, costs are cut by 17% in the last six months and by up to 40% for the final month of life because using expert teams reduces the number of end-of-life interventions and tests (Adler et al., 2009);
- patients who received integrated palliative care spent less time in intensive care and their healthcare costs were reduced by \$4,855 per patient (Gade et al. 2008).

In addition, Belgian, Italian, Spanish, Israeli, British, Australian, French and Canadian studies all arrive at similar conclusions (ACSP, 2012; Menten et al., 2010, Smith et al., 2013).



## An integral part of the continuum on a global scale

The urologist informs Jean that he has a rare cancer which is very aggressive and incurable. "If you're lucky, very lucky, you have a year, a year and a half, maximum," says the doctor to him. He recommends Tylenol if the pain gets worse and signs Jean's medical certificate. Encumbered with a catheter and a drainage bag, Jean struggles to walk.

At the hospital exit, Julie and Jean are devastated by the word "incurable". Back at home, the couple is overcome with worry. How will the disease progress? How will Julie take care of Jean alone? She worries about the bandage and the catheter which neither of them knows how to handle. Nothing was explained to them. The couple's financial resources are limited and the disease aggravates their situation. The days that follow are characterized by anguish.

The couple received help when Julie, at the end of her tether and anxious, went to the CLSC a week later. "The start of palliative care was a real relief. It helped us get organized, understand the different stages, alleviate Jean's pain, and manage his medications," says Julie.

*Ste-Agathe*



The professionals to whom this story is related are outraged, but not surprised. This "abandonment" of patients, some of whom never receive palliative care, is not an exception. Every day, they meet patients who were not referred to palliative care at the onset of the terminal stage and who after weeks and sometimes months of pain and uncontrolled symptoms, find themselves in emergency rooms accompanied by their exhausted and helpless loved ones. "Even patients who receive palliative chemotherapy need the expertise of palliative care teams for better pain, symptom, psychological and organizational management," says an oncologist.

The World Health Organization (WHO), which recognized the urgent need for palliative care in the continuum of care, tabled a resolution to this effect on January 23, 2014, whose preamble states that:

"palliative care is an ethical responsibility of health systems and it is the ethical duty of healthcare professionals to alleviate pain and suffering, whether physical, psychological, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and end-of-life care for individuals is among the critical components of palliative care."

In the first item of this resolution, the WHO urges member states to immediately:

"develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care and universal coverage schemes."

The early and gradual integration of palliative care, which the WHO recommends, has been unanimously recommended in specialized literature for the past few years. In England, Australia, and several European and Asian countries, oncology associations, palliative care institutions and research departments regularly publish recommendations and opinions that urge medical specialists to refer their patients sooner to palliative care teams. Closer to home, this is the case with the American Society of Clinical Oncology, the Canadian Medical Association and the *Direction québécoise de cancérologie*.

## From curative to palliative: still a difficult transition

Despite the consensus and the scientific evidence to prove the effectiveness of this approach, a still high percentage of patients were not referred to palliative care services or were referred very late in the cancer journey. In the vast majority of interviews conducted, the resistance of certain hematologists, oncologists and other specialists (respirologists, urologists, etc.) to refer or integrate the palliative care approach was highlighted as an obstacle to the transition from curative to palliative care and hence, to patients' access to these services.

In a series of publications on the integration of palliative care in Canada, the CHPCA maintains that:

"...a large number of first-line physicians haven't been trained in the palliative care approach. Clinicians who try to cure or "save" patients can be hesitant to integrate a palliative care approach or to steer patients towards palliative care providers. (...) These clinicians who have developed a bond with their chronically ill patients and who believe in the power of "hope" can find it difficult to say to someone that all therapeutic options have been exhausted, even if people are usually aware of being terminally ill {Fitzsimmons et al., 2007}. (...) Besides, clinicians often don't know what palliative care can offer. As a result of this attitude, patients are sent to palliative care an average of 30 to 60 days before dying {Bruera and Hui, 2012} when they are less likely to benefit from a treatment of symptoms and psychosocial support."

Also, this situation seems common, whether it's a patient being treated for years for cancer or a patient with a late diagnosis who is already in the terminal stage with just a few months left.



This is what Martine and Robert went through when the latter was diagnosed with advanced lung cancer. The respirologist refused to make a prognosis and referred him to another hospital for tests. On the

day of the bronchoscopy, during which Robert was weakened by a hemorrhage from the test, Martine asked to see the respirologist.

The conversation took place in the crowded waiting room: "Your husband has no chances of survival. No treatment is possible because the growth is too large and there are lots of metastases." Martine, in tears, asked if Robert knew about it. "No," said the doctor, "he didn't ask us. You can go home." The respirologist left without any other explanation.

For weeks, she was the only one to look after Robert as his condition deteriorated. The first respirologist did not talk about palliative care, but had Robert moved twice for tiring tests that contributed nothing new. Martine, at her wits' end, saw the family doctor who signed a medical certificate for her and referred her to the CLSC. "It was already very late. We needed feeding assistance and the hospital bed much earlier."

*Lacolle*

An oncologist who was told this story was indignant. "I want to believe that these are isolated cases, at least I hope that's what it is. Here, with a dedicated unit and home care services, we have a model of integration that enables us to refer our patients quickly to palliative care. And it's an essential resource both for the medical specialist, who doesn't feel as if the patient has been abandoned, and for the patient, whose symptoms, pain and distress will be better handled."

Even when resources are at hand, referrals aren't always made readily:

"We started an external day clinic for palliative care with a doctor and nurse available and we notice unfortunately that even our own doctors don't refer patients there, so the clinic is deserted although we know that patients can use it," says an oncologist who is the medical director of the cancerology department in a hospital. "It's not the case with all doctors, but there is still resistance and we're trying to understand the causes." The general practitioner who serves this clinic talks about a categorical refusal of some specialists to refer patients to palliative care. **What if all these specialists just simply needed information and support?**

## Care-Which-Must-Not-Be-Named

The interviews conducted indicate that the trouble isn't just a lack of human and financial resources and the way care is organized, but also the lack of understanding of what palliative care is or should be. As a result, patients refuse or put off this care believing that it is only associated with the last days of life and their state of health deteriorates more quickly, quality of life is reduced and they are subject to unnecessary suffering. The consequences: emergency room visits or hospitalization in acute care entailing a higher cost; family caregivers who get exhausted and families that fall apart.

Doctors, general practitioners or specialists turn their backs on this type of care, which they often judge as second-class medicine or "soft" care. Not to mention managers who don't understand the importance of training staff, dedicating units exclusively to palliative care or putting in place mechanisms that facilitate the curative to palliative transition.

"When starting out in palliative care services, I believed, like many others, that it involved handholding patients. I soon discovered to what extent I had to master nursing techniques to administer this care, particularly at home, and to ensure the comfort of patients who are struggling with pain and symptoms that are rare in curative therapy. We must know how to be resourceful and sometimes we need to innovate to bring better relief," says a palliative home care nurse.

"As this was the subject of my doctorate, I asked to be transferred to the palliative care unit of the hospital where I was working in acute care. The manager said to me, "It surprises me because you're a good nurse. So, why palliative care?" Her reaction clearly illustrates the picture that many workers in the network have of this care," says another specialized nurse.

In 2012, Dr Camilla Zimmermann, a CCS-funded researcher, showed that **Canadian oncologists take too long to send patients to specialized services in palliative care**. If 73% among them say that they have access to palliative care, only a third send their patients there after a terminal cancer diagnosis. Besides, a third of oncologists surveyed say that they would send their patients earlier to palliative care if this were called "support services".

It's also to facilitate the transition and encourage oncologists and specialists to refer their patients that a pivot nurse in a Montreal hospital urged her administration to create a pain

clinic. "Specialists find it easier to refer their patients to this clinic than to palliative care, so I can contact patients more quickly to explain the care and services to which they can have access depending on the progression of the disease," she says.

This initiative is not the only one. With pain clinics, symptom management clinics, oncology support services, etc., we get around the difficulty of talking about palliative care, both for doctors and patients. **Must this care be given another name or simply demystified? What's clear is that strategies must be developed to make palliative care better known and promote its integration early in the patient's trajectory.**

"Patients' openness to receiving palliative care depends on their knowledge of the nature of this care. They must be appropriately informed by members of the healthcare team. It is important for people living with cancer to know that they have entered the palliative phase to ensure the success of the transition. The doctor's attempt to "protect" the patient from bad news and way of presenting treatment options can influence the patient's involvement and the transition." (Lavoie, 2014)



## From theory to practice: the Verdun model

The integration of palliative care in the continuum of care is the basis of the model developed by the *Centre de santé et de services sociaux (CSSS) de Verdun*, recognized currently as one of the best practices in Quebec.

This is what one of the doctors who introduced this model has to say: "Palliative care is the expertise of adapting nursing and medical care to the intensity of the disease and the symptoms of the patient. To develop the Verdun model, we drew inspiration from what is being done in England, Scandinavia and New Zealand, where ambulatory palliative care is working well and the home death rate is much higher than here.

In our model, we divide palliative care into two groups. The first is made up of patients who have a gloomy prognosis for an incurable disease, but whose condition is stable. They are relatively independent. These patients can be treated through the current home care support services of the CLSC, if required, with house calls by the family doctor who, like the nurses in the program, can have access to the palliative care team's expertise, if necessary.

The second group consists of patients whose end is nearer and whose condition is unstable (convulsions, pain attacks, haemorrhages, loss of consciousness, difficulty swallowing or breathing, throwing up food, etc.) These patients need a number at the other end of which trained nurses and doctors dedicated to intensive palliative care are available 24/7. The word "intensive" is important in this model. At the end of life, the care that is needed the most is intensive care, whether at home or in a palliative care bed."



## Dying at home: ideal and reality

Dying at home is what 69% of Quebecers wish for, according to a survey commissioned by the CCS. (Léger, 2013). But according to experts, this wish is realistic for just slightly over 50% of patients.

In some CSSSs, palliative care services are organized and integrated into a continuum of care. The situation is not perfect, but the "model" works. **At the CSSS de Verdun, the home death rate of patients in palliative care is greater than 50% (CSSS Verdun, 2014). Elsewhere, the reality is quite different: less than 10% of Quebecers die at home.** It's the lowest rate in Canada and one of the lowest among Western countries such as the United Kingdom, Australia or the United States (INSPQ, 2006).

"The Canadian Partnership Against Cancer has determined that between 2005 and 2009, around 70% of cancer patients died in hospital (including emergency services and other types of institutions) and 11% at home. The Partnership's study included Quebec, where the percentage of hospital deaths among patients living with cancer was the highest." (CIHI, 2013). In fact, it's in Quebec and Manitoba that the hospital death rates are the highest, that is 86% of deaths, while the lowest rate, 49.5%, was recorded in British Columbia (CRS, 2011).

**This low percentage of home deaths may be explained largely by the limited access to home palliative care.** Even today, in 2014, a certain number of CSSSs (20% according to the most recent statistics published [DQC, 2012]) don't have any palliative care teams for home care. It's not unusual for just one of the CLSCs to offer the service, but the CSSS has many of them. It's a disappointing situation given that the End-of-Life Palliative Care Policy, adopted 10 years ago, prioritized: (...) the development of first-line services to maintain users as long as possible in their habitual environment if they so wish and if their condition allows it.

The number of hours allotted to home services also seems inadequate, especially for terminally ill patients. Family caregivers cannot look after patients day and night on their own. In some regions, the contribution of community services or volunteers can bring partial relief to families, but this help isn't always available or sufficient. "If we could offer night-time

sitters, we could often prevent hospitalizations or emergency room deaths. The costs would be lower and at the same time, we could help preserve the health of family caregivers," says a specialized nurse.

The composition of teams is also oddly random: some CLSCs have dedicated multidisciplinary teams, including one, two or three trained doctors, while in others all the services are provided by the regular home care support services team where the nurses have neither the training nor the access to specialized resources. Regular home care support cannot substitute for palliative care, especially in end-of-life scenarios. In other cases, nurses are not specialized, but can refer patients to another nurse in "regional" palliative care. The presence, training and number of home care doctors are also variable.

This variability has an impact on patients: "I work with patients in different CLSCs and not all are as lucky," says another specialized nurse in a palliative care organization. "For instance, in one of the CLSCs, we have three doctors for home care support services, but none is trained in palliative care and only one shows some interest. If the patient had been treated by an oncologist in a hospital, where a pivot nurse can act as an intermediary and get the prescription changed, or if for instance, there is a day centre where the patient can receive some treatments, we can manage, but if this is not the case, then it's the emergency room and sometimes unnecessary, stressful and expensive hospitalization."

External clinics where patients can be seen for drug dosage adjustments, the treatment of some symptoms as well as for medical appointments and tests are another important element in home care. These clinics help the patient avoid emergency room visits and receive better treatment at home. Unfortunately, they are still too few and some regions don't have them.

These situations are all the more regrettable because we know that patients who receive adequate palliative care at home are less frequently admitted to emergency rooms: 10.6 days on average in hospital and three emergency room visits against 15.9 days in hospital and five emergency room visits for patients who don't receive adequate care (Byockn et al., 2006).

If professionals think that dying at home is a possibility for only 50% of patients, it's because sometimes there is no family caregiver present or this person is too old or sick, has a cancer that requires complex treatments or carries too great a risk of complications, or even that the home has not been adapted for the patient's comfort.

"To die at home, we must have the resources, family caregivers and services. And this is far from being the case for a lot of people. Nurses who work in CLSCs tell us horror stories. In pathetic cases, such as the patient left by himself, the nurse or attendant must open the door with a hidden key because he is alone and can't come to the door. The patient is soiled and suffering. It's unacceptable! Here, in the hospital emergency room, we sometimes receive patients who are extremely ill and suffering, who've been lying on their sofa for the past four months without home palliative care." This outcry is from a nurse working in the palliative care unit of a major hospital.

In England, where the number of home deaths is much higher than here, experts believe that the healthcare system saves the equivalent of nearly CAD \$1,600 for each user who does



When Monique, her companion of more than 38 years, found out that she had been diagnosed with visceral pleural invasion, a form of advanced lung cancer, and her months were numbered, she didn't hesitate for a moment. Denise would be looked after at home and die as they had always promised each other. The oncologist reassured her and the pivot nurse had already transferred her file to the doctor and the palliative care team at the CLSC. In less than 48 hours, the services began, a hospital bed was brought in, and the CLSC's healthcare team was very present and complemented by a community organization which offered night nursing care to help Monique recuperate. The doctor who made regular visits was available round the clock. Denise had intense moments and tied up loose ends with her loved ones. A few weeks later, she died, surrounded by her family and friends. "I am so happy to have been able to let her live until the end in the intimacy and comfort of our home. She had lovely moments and said she felt she was being treated like a princess. But without the support of the palliative healthcare team and the presence of the night nurses, I could have never done it."

*Verdun*

not die in hospital (NELCIN, 2012). According to the CHPCA, the average cost of end-of-life care in Canada for a life-threatening disease like cancer is on average \$36,000 in an institution and \$16,000 at home. Savings for the healthcare system aside, dying at home should be based on a solid network. That's why it's not the only solution. Patients and their families must be allowed to choose. The alternative: palliative care units and hospices. There again, patients don't all have the same access to resources.



## The pivot of successful home care

Another essential point in the success of home care is the presence of a palliative care pivot nurse from the hospital who can take charge of the general assessment of the patient, the family and organizational background, and psychological state before referral to home care support services and then provide the liaison with an oncologist or a specialist as needed.

"The pivot nurse is essential to the continuum of care," says the associate executive director of a CSSS. This is echoed by almost all healthcare workers and also family caregivers.

"When my first partner faced cancer in the palliative stage, we received services, but I had to do everything alone. It's often complicated and requires a lot of time and energy. When my second partner also had colon cancer, the pivot nurse at the hospital made all the difference. She was the link between the doctor, CLSC, oncologist and pharmacy and she was able to help me understand the steps," says Nadine, a family caregiver, whose partner died at home. The processes were so complex that an analyst said the transfer of files from the hospital to the hospital to the family doctor or palliative care could take several days, even weeks!

"Ideally, the palliative care pivot nurse also draws up an end-of-life care plan by proceeding with preadmission in a hospice in cases where the patient would not want to or be able to die at home. By contacting the hospices myself and talking about it with the patient or family, I make sure that plan B will work," says a pivot nurse at palliative care day clinic in a hospital.

## Well-equipped with beds

Visiting day in a major Montreal hospital. The palliative care unit visited has 12 beds of which eight are in private rooms. It's very quiet. The staff who work there speak softly and are trained in palliative care. The teams who work there are dedicated, that is, the nurses and other healthcare professionals there work only with terminal patients. The team has two full-time psychologists. A part-time art therapist and massage therapist also work there. Patients, their families and even the staff receive psychological support.

Another visit, this time, in a hospital in Montérégie. The scenario is completely different. The doors to the palliative care unit are open despite the doctor's repeated requests to the contrary. The corridors are cluttered with trolleys. Out of 12 beds, only three are in private rooms.

Staff members talk to each other loudly from one end of the corridor to another and the ambience is the same as the adjacent acute care unit. A music therapist comes there regularly, but there is no other related service except for volunteer visits.

A patient tells his story. During the first few days in the unit, he had the impression that the staff ignored him and spoke to him curtly. A nurse he managed to soften up explained the reason for this attitude: he had asked for his door to be closed all the time and not to be woken up at night. These requests were deemed temperamental by the staff.

However, the majority of adults likely to receive palliative care have institutional deaths: 47.6% in short-term beds (50% for cancer patients); 8.1% in palliative care units; and 6% in

emergency rooms. More than 43.3% of these patients go to the emergency room at least once in the last few weeks of their lives (INSPQ, 2006). The shortage of units and hospices as well as the limited number of beds translate into death in the chaos of emergency rooms, in unconducive acute care beds or at home in extremely difficult conditions both for patients and their loved ones.

The government has fixed the ratio of 1 dedicated palliative care bed to every 10,000 inhabitants (1.18 beds per 10,000 inhabitants in France) as a standard. The *ministère de la Santé et des Services sociaux (MSSS)* hopes to achieve this goal in 2015. It's difficult to ascertain if this ratio is sufficient because these beds are distributed unevenly by region and institution. In Montreal, for instance, no additional bed has been planned and it will be short of nearly 20 to reach the target of 198 beds in 2015. These forecasts also do not take into account patients with a prognosis of two to eight months who cannot be kept at home and need to be put in long-term beds.

Several factors need to be considered where the number of beds is concerned. Some regions seem to outdo the ratio, but all their beds are found in the same hospice and hospital beds are not counted by unit. Other CSSSs have dedicated beds in hospitals, but distributed in different departments. In some cases, a palliative care team goes from bed to bed while in others, it's the acute care staff who attend to these patients even though they are not trained in palliative care. The professionals interviewed deplore the fact that palliative care beds are not grouped into dedicated units. And all say that a dedicated bed should be coupled with a qualified and dedicated healthcare team that includes doctors.

Besides, the government is investing in creating more hospices. The increase in the ministerial subsidy from \$60,000 to \$68,000 per bed at the beginning of 2014 will certainly contribute to the development of the hospice network and help maintain its services. In April 2014, there were 31 hospices for a total of 239 beds and eight hospices in the drawing board stage. The expertise and reputation of some of these hospices, like the Maison Michel-Sarrazin in Quebec City or the Maison Victor-Gadbois in Montérégie, are well established. They have also contributed to the training of many professionals and the integration of care in their region.

Even if some professionals express reservations, particularly on the relevance of increasing the number of these hospices in Montreal because of the high cost of buildings and the restricted number of beds that this would create, these hospices respond to an obvious need and patient demand.

And in CHSLDs? As surprising as this may seem, palliative care is slow to enter CHSLDs. However, thousands of Quebecers die in them each year, many of them from cancer. Despite the goodwill and experience of professionals and aides who work there, the management of symptoms, particularly the pain experienced by terminally ill patients, leaves much to be desired, according to several healthcare professionals.

"General practitioners working in these institutions are not familiar with the latest drug regimes," says a palliative care doctor. The problem seems serious and worries some palliative care doctors and nurses. **"It doesn't make sense that the palliative approach hasn't been integrated into these institutions where so many people die each year,"** says a clinical administrative manager of a home palliative care service.

Palliative care units that are currently being developed in CHSLDs are in fact dedicated first and foremost to terminal patients who receive care at home from their CSSS. In some cases, the doctor and nurses of this specialized unit provide support to the nurses and doctors of the CHSLD's regular units, but this is not systematic. **As a result, in many CHSLDs there is no palliative care resource, neither for regular nor regional clients.** The accelerated set-up of end-of-life palliative care units, even extended palliative care units, would certainly respond to a need and would prove without doubt to be less expensive than keeping a patient in hospital. A European study has shown that palliative care administered in long-term care homes cost €388 per day against €482 in hospitals (Tibi-Levy et al., 2006).

In brief, the professionals interviewed are unanimous in demanding more beds, but they insist that these beds must also be distributed according to actual needs in the region. **More beds, yes, they tell us, but also more trained healthcare staff and above all, more resources for home care.** "The increase in the number of beds will not resolve all the problems related to access and the quality



of services,” says a clinical administrative manager of a hospice.

What should be the standards, the basic services, and the rules of conduct in the palliative care unit of a hospital or CHSLD? The healthcare professionals and family caregivers interviewed all want private rooms, units dedicated exclusively to palliative care, trained staff, psychosocial support services and an atmosphere that is quiet and conducive to the care of the terminally ill. How can such a great disparity in the quality and nature of services offered to citizens be justified?



### **Extended care: glaring needs and non-existent resources**

Oncologists, doctors and clinical administrative managers have also been unanimous in demanding resources for patients with a prognosis of between two and eight months of survival who cannot be cared for at home. But the admission criteria and operation of units as well as specialized care homes are geared towards patients with a prognosis of less than two months. In fact, the average stay in these homes and units is less than three weeks. **“Oncology beds in acute care are filled with patients who could be moved to other extended palliative care units, a kind of intermediate resource in the network. It’s currently a glaring need,”** says an oncologist.

“These patients, who often live alone, are really helpless and the CLSCs can’t provide as many hours of services for that long. Extended palliative care units must be developed where treatments will be adapted and administered by trained and dedicated teams,” says a clinical administrative manager.

“The need is growing so much that I fought to obtain four beds reserved for this patient category in a unit of the regional CHSLD, but that will only respond to the need partially,” says a doctor.



## Doctors... the cornerstone

The development and improvement of palliative care, at home or elsewhere, obviously involves doctors. Firstly, hemato-oncologists and other specialists who must refer patients as soon as they are diagnosed with terminal cancer and work with palliative care teams, even as they continue treatment. Then, also as vital, family doctors who must do more for terminal patients by getting trained in palliative care in larger numbers and act as “coordinators”.

**Their role in home care is particularly crucial: “Home palliative care cannot be effective without doctors who are trained and available for the team.”** In the first few months, when the patient’s condition is still stable, the family doctor must get involved, agree to make house calls and make referrals, if necessary. But for the final months or weeks, when the patient’s condition is deteriorating, the presence of a palliative care doctor is essential. Nurses do almost all the work, but they must be able to contact a doctor at all times for dosage adjustments and emergency situations. **Even if there are many trained nurses and the team is multidisciplinary and dedicated, if they don’t have access to a doctor, there will inevitably be trips to the emergency room and sometimes, hospitalization,”** says a medical specialist.

It’s a huge challenge to involve family doctors in palliative care if we consider the number of Quebecers who don’t have a family doctor, which is 21% of the population (ISQ, 2013). Even if it’s a patient that they know, family doctors don’t necessarily have all the tools to broach the subject of palliative care and end-of-life scenarios. In England, 60% of general practitioners have trouble talking about palliative care and end-of-life scenarios with their patients without training and adapted communication tools (DMC, 2010). Training them in palliative care is a central issue.

Given the little appeal that palliative care has to new cohorts, even more so where home care is concerned, some professionals think that the payment schedule for house calls must be reviewed in a bid to boost interest in the practice. This is in an indispensable incentive, according to them, to attract new doctors.

“A doctor who sits in a comfortable office to vaccinate a baby is paid the same hourly rate as someone who will have to brave the snow to make a house call to attend to a suffering patient in severe pain or with chronic sores. Not to mention that the doctor who is a part of our team will be called 10 or 12 times per week at any hour to attend to an emergency. It doesn’t make sense that this is not financially recognized. Pay must be increased reasonably and reflect a mixed remuneration based on the hourly rate as well as the number of patients handled. In addition, house calls must be better paid than office consultation,” says a palliative care doctor.



## Training... a sine qua non

In its resolution on the integration of palliative care tabled in January 2014, the **WHO highlights the importance of integrating palliative care into the basic and professional development of service providers, particularly in the first year of the medical course.** The resolution also states that:

“Intermediate training should be offered to all healthcare agents who work regularly with patients having potentially life-threatening diseases, including healthcare agents in oncology (...) and specialized training in palliative care should be offered to healthcare professionals who will be responsible for integrated care for patients whose needs go beyond routine symptom management.”

All the professionals, managers, and family caregivers we interviewed underscored the importance and urgency of adequately training palliative care staff, including healthcare aides. In 40 years, knowledge, drugs and techniques in palliative care have advanced, but even today, professionals who want to specialize in it must seek their own training and pay for it out of their pockets in many cases while the institution for which they work doesn’t give them leave of absence to pursue it. However, palliative care demands not only highly specialized knowledge of symptoms, care techniques, pain as well as drugs and their effects, but also good people skills in approaching patients and their loved ones. For the first time, in 2013, the Université de Montréal’s final year students in family medicine had an integrated and mandatory block of 90 minutes on palliative care.

Without training, aptitude and an interest in palliative care, staff can't effectively treat terminal patients or interact sufficiently with them or their caregivers. They also risk getting demoralized. The turnover of staff in units where staff training and selection are not adequate has been pointed out by several professionals. On the other hand, in hospices, specialized units in well-organized hospitals and dedicated palliative care teams in CLSCs, the rate of retention of nurses in particular often exceeds 90%.

**"It's inconceivable that I must undergo training for three months to be able to work in intensive care, but none to work in a palliative care unit,"** says a specialized nurse in Quebec. "Basic training and professional development are essential not only for nurses, but also for doctors and all those who work in palliative care," says a nurse who teaches palliative care nursing.

## Conclusions

The ageing population, longer life expectancy and the transformation of diseases such as cancer into chronic illnesses present new challenges to our healthcare system and give rise to increased needs, which includes palliative care. Focusing on an individual's quality of life, palliative care supports patients and their loved ones through difficult transitional periods. Palliative care is very much in order but it must be better organized to occupy the place it deserves.

Healthcare professionals will also have to change their practices. Lack of time, training and information on existing palliative care services, difficulty letting go, difficulty managing the reaction of patients or talking about the end of the curative phase, organization of care within the department and absence of a pivot nurse, political will or organizational culture are several factors that explain the difficult curative to palliative transition. And this status quo contributes without doubt to limiting many patients' access to palliative care.

**The scientific consensus on palliative care is solid and our collective responsibility to act is very clear: palliative care has beneficial effects on those who receive it as it not only enhances their quality of life, but can also prolong their life span.** Fulfilling the aspirations of patients -and more effective, efficient and economical to boot - palliative care is a hands down winner in all respects. With a policy in place and a recently passed legislation, we're right to ask what's holding back

the development of palliative care. If there are many answers, ranging from inadequate training to the culture of curative treatment at any cost, we only need to look to the advocates of palliative care to realize that functional models do exist and just need to be adopted and adapted across Quebec.

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The testimonials included in this document are true. Names have been changed to protect the privacy of the individuals mentioned.

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