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# QUEBEC END-OF-LIFE PALLIATIVE CARE POLICY

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English Translation





## **A Word from the Minister**

All persons who experience serious health problems expect to receive the best quality healthcare possible, and a civic-minded society such as ours does its utmost to ensure as much. But there comes a time when, despite people's best wishes and the efforts of highly qualified professionals, a cure is no longer possible. We must then be able to comfort children, adolescents, adults, and the elderly in the final stage of their lives. This requires clear guidelines and compassion, and it is exactly these ideas that served for the writing of this *End-of-Life Palliative Care Policy*, which will guide our actions from now on.

The result of extensive consultations, this policy is aimed at improving the accessibility, continuity, and quality of care and support services we wish to offer our loved ones at the end of life. These services must be planned and offered to respect their needs and choices, as well as the expectations of their families. This demands both flexible care and diverse settings in which to provide it, from the end-of-life patient's home to specialized palliative care units. The policy aims specifically to provide timely, quality services in the proper setting.

It is only through real dialogue between end-of-life patients and their families, with volunteers, and with health and social services workers that these services can be clearly defined and properly implemented. Discussing together also helps shed light on the psychological and spiritual dimensions of the end-of-life experience and address them appropriately, as one would physical symptoms. Such a dialogue is made easier by an interdisciplinary approach and the important contribution of volunteers and community organizations, all aspects that figure in the policy.

This document gives us an opportunity to take a compassionate look at the wellbeing of our loved ones as they near the end of their lives. Let's take it to heart and use it to communally and collectively provide them the services we would like to receive ourselves.



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## **Introduction**



## Introduction

Ongoing changes in medicine, medical technology, and therapies; improving living conditions and lifestyles; and all other methods that increase lifespan in no way change the inescapable nature of death. Each person will one day face disease, then death—either his or her own or that of a loved one. Children, adults, the elderly, men and women from all backgrounds are all drawing closer to this final stage of their existence. For families,<sup>1</sup> grieving for loved ones is a time of adjustment and even crisis, marked by pain and fragility.

Volunteers and caregivers from numerous disciplines continue to be called on to treat patients and alleviate physical and moral suffering. Currently, the attitude of many people suggests that death has become a taboo. This taboo persists because end-of-life patients and their families are often very vulnerable and unable to demand rights and services. Society's attitude toward death is also influenced by the feeling of relative security that comes from technical advances in modern medicine.

Current ways of caring for clientele in need of palliative care raise questions about the accessibility, fairness, and continuity of services. This is where ethics come into play. Decisions regarding palliative care are a very heavy burden for families and caregivers. In addition, today many people still die in unnecessary agony because their symptoms and pain are not properly controlled. What's more, without clear guidelines, missteps can occur—therapy can be overaggressive or abandoned altogether, and there can even be an increase in euthanasia.

Québec society must therefore provide quality services to an increasing number of end-of-life patients. Demographic trends are revealing in this respect. As the Clair Commission (2000) report stressed, Québec's population is aging rapidly, which will lead to a sharp and inevitable increase in the number of deaths in coming years. The bulk of these deaths will be due to diseases that will require palliative care.

The need and urgency for Québec to draft a palliative care policy have been borne out in numerous recent publications. More fundamentally, healthcare workers themselves are calling for this policy, to have the tools they need to organize services and better plan the care they provide.

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<sup>1</sup> For the purposes of this policy, families are the people who provide significant regular or occasional care to a sick person. They belong to the person's immediate circle. They may be a member of the family or a friend.

This policy is the result of consulting and working with healthcare professionals. Palliative care experts and healthcare staff were consulted extensively as part of a study funded by Ministère de la Santé et des Services sociaux (MSSS).<sup>2</sup> The policy is also the result of diligent efforts by an advisory committee put together by MSSS. This committee's makeup was representative of various palliative care fields and included representatives from the health and social services network. While carrying out its work, the advisory committee also met with people in strategic positions in the field. In terms of pediatrics, a working group drew attention to this clientele's unique needs. A consultation with organizations involved also helped validate certain proposals regarding people with HIV/AIDS. Health network anticancer organizations were also involved in drafting the policy. Lastly, the document was the subject of a targeted consultation with organizations interested in the issue.

The first chapter of the document is devoted to defining palliative care. The second discusses the demographic, social, and cultural contexts of this policy. The third defines the scope of palliative care and the policy. The fourth describes the current organizational context. The fifth presents the guiding principles underpinning the policy. The sixth describes the vision governing the operation and organization of services in Québec. The seventh sheds light on the unique needs of pediatric patients. The sharing of responsibilities at different levels, the distribution of resources, and accountability are discussed in chapter eight. Chapter nine presents policy follow-up and evaluation measures.

A case study of an end-of-life cancer patient is available at the end of the document. It relates the patient's clinical and administrative experience in relation to the various aspects of the policy.

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<sup>2</sup> LAMBERT, P., and M. LECOMTE, *Le citoyen : une personne du début à la fin de sa vie, Rapport sur l'état de situation des soins palliatifs au Québec*, March 2000.

## **1. Defining Palliative Care**





## **1. Defining Palliative Care**

Palliative care appeared in Québec some thirty years ago to meet the needs of people with an incurable disease that seriously compromised their survival. It follows a unique care philosophy, which takes a holistic approach offering new outlooks and includes a series of measures to humanize care for patients and their families. According to the World Health Organization (WHO) definition, “Palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.<sup>3</sup>” WHO further stresses that “Palliative care affirms life and regards dying as a normal process, neither hastens nor postpones death, provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death.”

### **Underlying Values**

This policy uses the WHO definition of palliative care. However, like Canadian and Québec palliative care associations, it also reaffirms certain values intended to guide palliative care services, namely

- The intrinsic value of each person as a unique individual, the value of life, and the inescapable nature of death
- The necessary participation of patients through their free and informed consent to ensure they are party to decisions in accordance with their wishes on all matters concerning them, including their true condition, and that their choices are respected
- The duty of confidentiality on the part of caregivers, which prevents the release of personal information without patient authorization
- The right to compassionate caregiver services respectful of what provides meaning to people’s lives—their values, culture, beliefs, and religious practices and those of their families

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<sup>3</sup> World Health Organization.



## **2. The Sociodemographic and Cultural Context of the Policy**



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### **2.1 The Demographic Context**

Like many Western societies, Québec's population will age quickly in coming decades. For example, the number of people aged 65 or over, which was 13% in 2001, will hit 30% in 2041. This aging of the population has sizable repercussions on the health and social services needs of end-of-life patients.

The aging of the population will inevitably lead to a substantial increase in the number of deaths. From 56,780 in 2000, this number will rise to 69,720 (+23%) in 2015 and 101,289 (+78%) in 2050<sup>4</sup>. These increases will affect the very elderly in particular, who account for the greatest number of deaths. There will therefore be a high concentration of deaths among the very old.

These trends will lead to an increase in the number of people with progressive, often chronic diseases. In theory, most of these diseases increase the demand for end-of-life palliative care. Given that most people who do not die suddenly may need palliative care at least for a short while, it is not hard to imagine the effects this phenomenon may have on palliative care.

In light of this, is our society ready to face such a high death rate? Overall, Québec society is not ready to deal with such a large number of deaths in such a short period of time, with all the attendant psychological and social consequences. Consequently, experts believe putting in place effective services is a major and pressing challenge.

### **2.2 The Social and Cultural Context**

Other sociological factors influence how the end of life is faced. People—notably the elderly—are increasingly alone and isolated and can no longer count on the support and comfort of their families, as they once could when society was more rural and families were more traditional. With low birth rates, family breakups, economic diversification, as well as the urbanization of society and the corresponding rural exodus, people no longer live in the same community their whole lives and no longer have the same natural ties. The result is that more and more people—particularly in cities—have no families to rely on at the end of life.

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<sup>4</sup> Institut de la Statistique du Québec, *Perspectives de la population du Québec, 1996-2051*, based on the reference scenario.

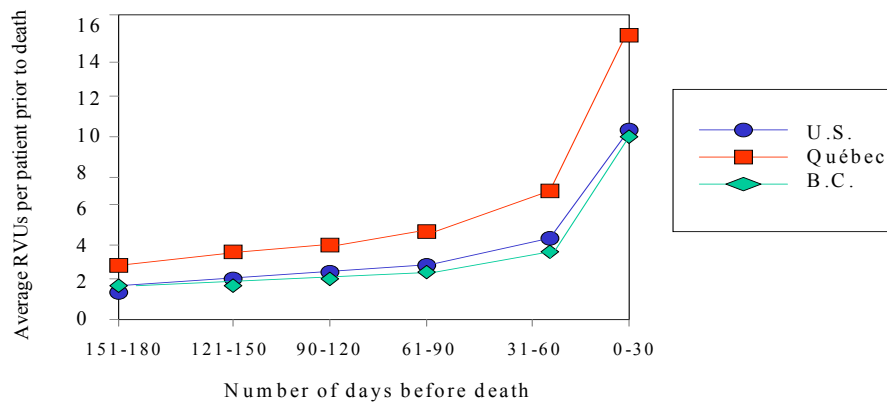
### *Social values regarding death*

Another challenge is society's attitudes toward death. Like most Western societies, Québec tends to be in denial about death; it remains a taboo among individuals and in society. Yet, like birth, death is a natural phenomenon we all must experience. This uneasiness with death raises questions about our fundamental values. Numerous factors have led us to remove death from our thoughts. These factors are addressed in the complete version of the policy available on the MSSS website.

### *Social values that influence healthcare system priorities*

As study results show,<sup>5</sup> Québec takes a very active approach to exams and treatments up until the very end of life. In terms of services provided in the last six months of life, Québec physicians are much more aggressive than their colleagues in the U.S. and British Columbia. Treatment is provided in each month prior to death. However, it is stepped up even more in the last two months, particularly in the last month, as shown in Figure 1.

**FIGURE 1 Use of medical services by the elderly in the last six months of life**



### **RVUs: Relative value units**

<sup>5</sup> LATIMER *et al.*, "Utilization of physician services at the end of life: Differences between the United States and Canada," in *Inquiry*, vol. 36, 1999, p. 90-100.

In Québec, the closer death is, the greater the number of diagnostic tests, medical and surgical treatments, and even incidences of major surgery. Since the ability to cure is certainly no greater in Québec than in other Canadian provinces or the U.S., it is appropriate in light of these statistics to examine our ways of treating end-of-life patients.

#### *Values that influence how we treat end-of-life patients*

Values and attitudes toward death also influence how healthcare professionals treat patients. Caregivers often see death as a failure. Faced with a disease with an inescapable outcome, some healthcare professionals tend to withdraw from patients. According to Eissler<sup>6</sup> and others, healthcare professionals (like the general public) are more scared of their own death than that of patients, while tending to deny this existential reaction.

But, as Brasset and Lajoie<sup>7</sup> stress, it is not death that is the problem, but a life that has become increasingly difficult at a physical, psychological, and social level and is causing pain and suffering. According to them, personal notions of death color our understanding of end-of-life care.

This has serious consequences that can extend to society as a whole, affecting how much importance is accorded palliative care and quality of services. It is why, despite our evolving society and its values of solidarity and social justice, people still die each day in inhuman conditions, as certain works have revealed.<sup>8</sup>

#### *Taking cultural diversity into account*

Over the last few decades, Québec has undergone many changes, and this rate of change is likely to intensify. Our culture is increasingly diverse, particularly in urban centers. This manifests itself in various ways, depending on the age and background of each person.

How we deal with significant events like birth and marriage is influenced by our culture and communities. The same applies to the last moments of life. This period is marked by events and situations where values, rituals, cultural traditions, and religious and spiritual beliefs are of key importance, both for patients and their families.

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<sup>6</sup> EISSLER, K.R. *The psychiatrist and the dying patient*, New York, I.U.P. Inc., 1955.

<sup>7</sup> BRASSET M., and R. LAJOIE, AQSP Newsletter, Public Health Branch, Régie régionale de la santé et des services sociaux du Saguenay–Lac-Saint-Jean, February 2002.

<sup>8</sup> Such as the Lambert-Lecomte report on palliative care in Québec, March 2000.

When death is near, many people feel the need to take stock of and give meaning to their lives. In this search for meaning, they seek answers in their traditions and beliefs. It is therefore necessary to plan and provide services that take a flexible approach to various cultures. However, one's membership in a cultural community cannot alone determine treatment. Each person's situation is unique, which can influence his or her needs. Palliative care must take this into account.



### **3. The Scope of Palliative Care**



### **3. The Scope of Palliative Care**

#### **3.1 Palliative Care: For Whom?**

Palliative care is designed for clientele of all ages and from all social backgrounds with incurable diseases or age-related illnesses. It is also for patients' families. It is a further help for patients struck down suddenly by disease, or victims of injuries that will soon cause death, if only to comfort families in the grieving process.

Palliative care is not limited—as it was when it first appeared—to cancer patients. Its personalized treatments are not aimed at curing patients, but alleviating the physical and psychological signs and symptoms that contribute to overall suffering at the end of life. Palliative care helps patients maintain their ability to decide on matters of concern to them and stay in touch with others.

End-of-life palliative care is the subject of this policy. It is aimed at people in the pre-terminal or terminal stage of a disease. The pre-terminal stage is most often the period when the disease progresses slowly and curative treatments have for the most part been abandoned. The terminal phase is associated with an often unstable clinical condition that causes rapid loss of autonomy. End-of-life palliative care is also aimed at patients' families—especially in terms of comfort and psychosocial support—throughout all stages of disease and grieving.

#### **3.2 The Decision to Seek Palliative Care**

The decision to treat seriously ill patients for palliative rather than curative purposes is a challenge, one that has strongly influenced the clinical and organizational elements of this policy. This decision has major repercussions on timely access to palliative services at the right facility.

##### **3.2.1 The Limitations of Vital Prognosis as an Administrative Criterion**

Historically in Québec, patients who needed palliative care were transferred to facilities with specialized palliative care units or hospice resources. Access to these facilities was subject to criteria, with vital prognosis generally being key. The essential criterion for taking a palliative rather than curative approach was often a vital prognosis of no more than a few months by the attending physician. This administrative rule is still a source of confusion and frustration in defining the scope of palliative care today.

This process gives physicians the power to use their clinical expertise to determine when palliative care is necessary. The implications of such a decision—the prognosis in particular—are obviously very important. However, this undue emphasis on vital prognosis does not do justice to the complexity of the process leading up to the decision to offer patients palliative care.

### **3.2.2 The Need to Be Well Informed and Supported When Making a Decision**

Palliative care becomes a progressive necessity for patients, which implies they are aware of their condition and accept the situation. Quite often, this awareness and acceptance are not easy to come by and are part of a personal journey marked by ambivalence between wanting to live as long as possible and letting death take its course. Palliative care cannot be imposed unilaterally and must be offered within a relationship of trust between patients, their physicians, and other members of the caregiving team. Respect for patients' autonomy requires that they be given the information and support they need to make an informed decision. Caregivers must take into consideration broader factors, and not just medical aspects. The role of caregivers, who have their own ideas and fears about death, is to help patients and families based on their needs, and facilitate communication in the process leading up to death.

### **3.2.3 Moving From a Curative to a Palliative Approach: The Problem of Referral and Orientation**

End-of-life decisions require a medical approach that takes into account the patient's condition and shows concern for his or her quality of life prior to death.

There is general agreement that patients are late to receive palliative care. This raises the question of when it is “timely” to refer patients to palliative facilities. On the one hand, some teams administer curative treatments that unduly prolong life. On the other hand, not all patients are referred to facilities that can meet their special needs in the palliative phase and are thus kept in curative settings, mainly hospitals.<sup>9</sup>

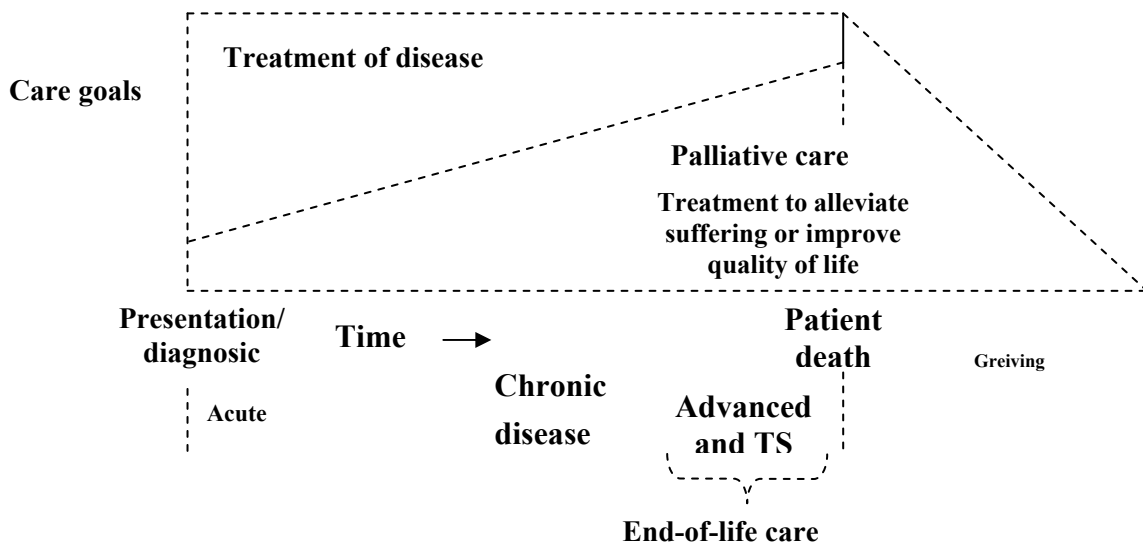
This policy aims to make palliative care progressively available from the moment a cure becomes improbable or unrealistic. Figure 2 illustrates the normal evolution of palliative care goals over time. These goals change as hope for a cure diminishes.

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<sup>9</sup> LAMBERT, P., and M. LECOMTE, *op. cit.*

The linear approach used in the figure is simplified. In fact, the combination of curative treatments and palliative care can vary over time based on the needs of patients and their families.

**FIGURE 2 Theoretical Evolution of Care Goals Over Time for Patients with an Incurable Disease<sup>10</sup>**



*Timely, systematic referral*

One prerequisite to increasing the rate of referral to palliative care is to ensure patients receive support and assistance when life-changing news is announced. If we are to build a relationship of trust, we must first show consideration for the emotions and existential crisis they feel upon learning they have cancer or suffer from amyotrophic lateral sclerosis or hepatic cirrhosis. This relationship will make it easier to accept the caregiving team’s suggestion to begin palliative treatment once the time comes, instead of continuing with curative measures that no longer work.

But more humane curative care management is not enough to smooth the transition to palliative care. This policy is aimed at increasing timely referrals to palliative care specialists and particularly to organizations that help keep patients in their home environments. And before we can systematically refer patients in need to palliative care, we must first understand potential roadblocks.

<sup>10</sup> Figure from Canadian Hospice Palliative Care Association. *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*, March 2002, p. 18.

### *A difficult situation for the medical profession*

Deciding to seek palliative care raises a number of issues. On the one hand are patients, who are entitled to the best treatment for their condition and whose freedom to make decisions must be respected. On the other hand are physicians, who are often seen by patients as experts in whom they can have absolute trust.

Physicians, who use knowledge and technology in their patient care, sometimes seem to have trouble resigning themselves to the fact that cutting-edge treatments are no longer having much effect and that it would be better for the patient's wellbeing to suggest palliative care. For many physicians, resorting to palliative care is an admission of powerlessness, or even failure.

The main challenge in moving from curative to palliative medicine is in managing uncertainty. According to Quill,<sup>11</sup> most physicians hesitate to be pessimistic with patients in their prognosis because of the uncertainty involved. Furthermore, physicians hesitate to discuss death with their patients for fear of losing their trust and making them feel abandoned. But according to the author, neglecting to provide information on prognosis and palliative care can cause pain and suffering for patients.

### *Managing uncertainty*

There are four different scenarios regarding serious illness prognosis. The extreme scenarios involve a very good or very bad prognosis, depending on the stage of the disease. In both cases, the prognosis is based on certainty, which strongly influences decisions. In the former scenario, this certainty will encourage patients and caregivers to choose curative measures, and in the latter, not to intervene and instead opt for palliative measures.

The other two scenarios are much more medically uncertain. Either the disease's progress is unclear, which makes it hard to formulate an opinion on the patient's future, or the prognosis, although gloomy, cannot preclude all hope of a cure. This uncertainty diminishes the influence of medical opinion and puts more emphasis on personal considerations such as patients' values, beliefs, quality of life, understanding of the benefits and drawbacks of possible treatments, previous experiences, fears, worries, social roles, and others. However, these personal considerations can themselves create uncertainty that will lead patients to rely heavily on medical opinion. It is by weighing these various elements against an uncertain prognosis that patients can decide whether to continue curative treatment or seek palliative care.

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<sup>11</sup> QUILL, T., "Initiating end-of-life discussions with seriously ill patients: Addressing the 'Elephant in the room'," in *Journal of the American Medical Association*, 2000; 284: 2502-2507

### *Using proven clinical criteria to facilitate decisions*

It seems that certain clinical criteria for determining the advisability of palliative care are underutilized. Insofar as possible, experts must develop criteria that can objectively guide decisions concerning, among other things, making the switch from curative treatment to palliative care. It is therefore crucial that the various professional organizations responsible for care quality reach a consensus.

### **3.3 Ethical Issues at End of Life**

Ethics play a key role in palliative care. Palliative care raises ethical questions with regard to the control patients and their families have over disease and death. Ethical questioning mainly arises with regard to refusing and stopping treatment, abandoning or aggressively pursuing therapy, opting for continuous sedation, or choosing euthanasia. Clinical research also raises ethical issues.

The notions of refusing and stopping treatment have been the subject of much jurisprudence<sup>12</sup> in Québec, across Canada, and in the U.S. that enshrines the right of patients to refuse any treatment, even if its sole goal is to prolong life.

Aggressive therapy refers to medical practices that are overly invasive for the benefits they provide. It is an obstacle to palliative care once curative measures no longer work, relegating to secondary status the goal of maintaining the best possible quality of life. Its opposite—the abandonment of therapy—can also be a threat, particularly for more vulnerable groups such as people with mental illnesses, physical or mental handicaps, or the elderly. We must avoid making palliative care the automatic fate of certain groups deemed somehow undeserving of full and complete conventional care.

The failure of palliative therapies is one of the more sensitive end-of-life problems. Despite quality palliative care, medications and various therapies may not have the desired effect on the patient's physical and moral suffering. Some physicians therefore resort to continuous sedation, which is an artificial, drug-induced coma. When continued up until death, continuous sedation poses ethical problems, notably because it may be confused with euthanasia,<sup>13</sup> without being called as such. Without guidelines, this practice is a concern for numerous palliative care specialists. Many of them have called for standards to be drafted to better regulate its use.

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<sup>12</sup> ROY, D.J., J.R. WILLIAMS, B.M. DICKENS and J.L. BEAUDOIN, “Les traitements de prolongation de vie,” in *La bioéthique: ses fondements et ses controverses*, Saint-Laurent, Éditions ERPI, 1995, p. 422-430.

<sup>13</sup> The sensitive issue of euthanasia also touches on palliative care and has stirred a veritable debate in society that this policy is not designed to address.

Clinical research, though needed to further knowledge, also raises very serious ethical questions, specifically with regard to people with a serious or incurable disease. When physicians offer to enroll patients in a research protocol, they must clearly explain that the treatments administered are experimental and unfortunately not proven to cure. Patients must be aware that at most they may prolong their lives, without guaranteeing the quality of life they would like. They also run the risk of compromising the quality of their final moments. The same applies to experimental palliative therapies, which must be presented for what they are.

Clinical research therefore requires close attention. Healthcare professionals have a duty to provide patients with comprehensive information on the status of their incurable disease and the experimental nature of the treatments. They must offer patients all the support they need, allow them to refuse or accept treatments, and permit them to change their mind during the protocol. The input of research ethics committees is crucial to ensuring the quality of the patient consent process.



## **4. The Organizational Context**



## 4. The Organizational Context<sup>14</sup>

### 4.1 Palliative Care Services

All regions of Québec offer palliative care services. However, despite the presence of numerous service providers and the efforts of caregivers to give the best care possible, these services are poorly organized and lack resources. Few regions made these services a priority in their 2002 regional organization plan.

In general, palliative care services develop on their own, not in response to increasing need, and without an overall vision or any real structure. Just like when they first appeared over thirty years ago, they still too often depend on the commitment and dedication of people sensitive to the needs of patients, particularly cancer patients. Palliative care was only officially recognized as a healthcare service in 1998, when it became one element of the Québec Cancer Control Program.

However, this recognition and official inclusion as a public service did not guarantee the availability of well-organized care, particularly for patients with diseases other than cancer.<sup>15</sup>

### 4.2 Access to Palliative Care Services

In Québec, palliative care is mainly provided in four settings:

- The home
- Hospitals
- Residential and long term care centers (CHSLD)
- Palliative care hospices

#### 4.2.1 The Home<sup>16</sup>

To meet the needs of those who wish to remain as long as possible in their home environment, CLSCs offer palliative care as part of the homecare support program and, to a lesser extent, as part of their regular services when patients and their families are mobile. These services help keep patients in their home environment.

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<sup>14</sup> Some information in this chapter comes from a 2002 report by MSSS's Québec Coordination Center in the Fight Against Cancer.

<sup>15</sup> MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX. *Programme québécois de lutte contre le cancer*, Ministère de la Santé et des Services sociaux, 1998.

<sup>16</sup> Home refers to the usual place of residence: House or private lodging, low-cost housing, retirement home, room and board.

All 147 CLSCs in Québec claim to serve people in the pre-terminal and terminal phase. The ability to respond quickly and appropriately to rising demand for services and family support at various times of the day to enable patients to live as long as possible at home is a major challenge.

The palliative services available vary geographically and the eligibility criteria are imprecise. In addition, caregiver responsibilities are not clearly defined. Currently, many CLSCs refer patients to hospitals as soon as their health deteriorates and it becomes hard to control symptoms.

Moreover, access to quality services of sufficient intensity remains subject to structural considerations such as the recognition of palliative services as a specialized component of the homecare program, the existence of teams with appropriate experience and expertise, the availability of resources, and other factors. Given this organizational context of scarce resources, the services available to program clientele must be prioritized. The needs are many, and priorities are generally established to the detriment of certain clientele.

A few CLSCs have developed a stabler organizational structure for end-of-life services. They have also created mechanisms to link resources such as nurses and social workers to physicians and pharmacists; other community resources may also be called on. Until recently, these relationships were based on service agreements. Service coordinators were appointed and measures were developed to accelerate patient management through open communication and effective information transfer. But this well-structured model is still uncommon in Québec. The implementation of laws adopted recently will correct certain shortcomings.

#### *Services offered by certain for-profit and non-profit organizations*

For-profit and non-profit organizations also help meet the need for palliative care. In this respect, Association d'entraide Ville-Marie (AEVM) and the Victorian Order of Nurses (VON) are two non-profit organizations that serve Montréal-Centre and Laval. Their services are designed for people with cancer and consist mainly of nursing care, relief care, supportive care and attention, and equipment loans. They are funded by patients (private insurance), subsidies, and donations.

For-profit homecare agencies also provide care and assistance, on a user-pay basis. Upon patient and family request, these agencies may assign nursing staff or attendants to patients in institutions. However, these workers may not be properly trained in palliative care.

#### *Home adaptation services and technical aids*

Home adaptation services, which are the responsibility of Société d'habitation du Québec (SHQ), are not appropriate for end-of-life patients. The wait time on applications is six months, which is much too long in an end-of-life palliative context. But above all, home adaptation is only required for a few weeks or months, depending on the progression of the disease, and SHQ programs are not designed for this type of situation.

Technical aid programs (beds, wheelchairs, etc.) are equally unsuited to the special needs of this clientele, which requires such aids for only a few days or weeks.

### **4.2.2 Hospitals**

Though virtually all hospitals offer palliative care services, the accessibility, intensity, and types of programs vary considerably from one institution to the next. Some have no real facilities, whereas others have developed specialized units for clienteles that require these services.

In hospitals, people often die in so-called “acute care” beds. They are cared for by a team composed of the attending physician and other staff assigned to the patient, generally without a palliative plan or idea of the range of end-of-life services needed. Many Québec hospitals set aside a certain number of beds for people in need of end-of-life care. These beds can be a single ward or spread throughout the institution. Care is provided by teams that may include healthcare professionals with expertise in the field, often a clinical nurse or advisory team. With the attending physician's consent, clinical nurses can provide daily patient follow-up. Some institutions, even though they have no specialized beds, rely on mobile multidisciplinary teams to serve hospitalized patients.

Some 20 Québec hospitals have developed end-of-life patient care units, with around 140 beds in total. Care is provided by interdisciplinary teams usually composed of nurses, physicians, social workers, pharmacists, and volunteers; often nutritionists, physiotherapists, occupational therapists, and pastoral associates; and sometimes psychologists and music therapists. Lastly, some hospitals offer outpatient services, which are usually provided at oncology clinics.

### **4.2.3 Residential and Long Term Care Centers (CHSLD)**

CHSLDs are home for many elderly and handicapped people. In fall 2001, public and private government-funded facilities—excluding psychiatric facilities—represented 40,065 beds in total. For their part, private facilities without government funding accounted for 3,230 beds.

The information provided by long term care centers indicates that only a few of them have set aside palliative care beds. As a general rule, these beds are not grouped together. There are around 110 in all CHSLDs across Québec put together, and they can accommodate both permanent residents and outpatients. The latter are referred to CHSLDs by CLSCs or hospitals seeking to transfer patients who can no longer benefit from curative measures. Though certain long term care centers have specialized palliative care teams, they are a tiny minority. Often care is provided by these institutions' healthcare teams.

### **4.2.4 Palliative Care Hospices**

There are 14 hospices<sup>17</sup> in Québec. They have 100 beds in total, mainly for adults with cancer. There are also 10 day center places at Maison Michel-Sarrazin. All hospices are non-profit organizations.

Most residents are in the terminal phase of their illness and are cared for by multidisciplinary teams. The composition of these teams may vary from one hospice to the next, but the core caregivers are physicians, nurses, social workers, and pastoral associates. Some also have client care attendants. Each hospice has a large number of volunteers.

Some are currently funded as community organizations under *Programme de subvention pour les organismes communautaires* (PSOC) or as *intermediate resources*, even though the number of hospices classified as such is low (one hospice officially recognized in 2004). Development agency subsidies are a key source of funds. Many hospices receive financial support and various kinds of help (staff, equipment loans, etc.) from institutions in their region.

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<sup>17</sup> This number excludes hospices in the planning stages.

Funding for these hospices is often sporadic. They must constantly work to ensure funding through fundraising campaigns and by soliciting donations. Because of this lack of recognition, other healthcare providers do not really see hospices as complementary resources, though this is changing.

Their status creates problems with respect to professional services. Under the *Act respecting health services and social services*, only institutions are entitled to offer these kinds of services. Unlike public healthcare institutions, most hospices have neither a quality assurance program nor an accreditation system.

We can expect demand for this type of resource to grow, especially since people wish to stay in their own homes for as long as possible. But for many people this will be impossible because of their condition or because they will be alone at the end of life, without the support of their families and the services they need to continue to live at home. Hospices will become an alternative for some of these people. It is therefore important to define their roles and responsibilities within the healthcare network as well as criteria to ensure their viability, while respecting their approaches. We must also ensure a true partnership between hospices and local service network development agencies as well as other service providers and review certain eligibility criteria regarding patient age and illness.

### **4.3 Human Resources**

Human resources are the heart of any organization. The quality of the response to patient needs depends on staff professionalism and personal dedication. Staff come from diverse backgrounds. The duties of caregiver groups must be well coordinated.

#### **4.3.1 Health and Social Services Stakeholders**

##### *Physician services*

Physicians are a key palliative care resource. Most regions have physicians whose practice is dedicated entirely to palliative care. Accordingly, though they are few compared to the total number of physicians, these physicians have developed a high level of expertise, notably in relieving physical pain.

Among the problems of a medical nature are the insufficiency or even total lack of adequate palliative care training, the lack of interest of many physicians in this type of care, the lack of availability to provide at-home follow-up, and the non-existence in numerous regions of Québec of organizations capable of providing phone support 24 hours a day, 7 days a week. The mode of physician remuneration, given the extensive needs of patients, is also one of the reasons why physicians hesitate to offer these services.

### *Nursing care*

Nurses are crucial to the relationship patients have with their families, other caregivers, and volunteers and directly influence service quality and continuity.

Some nurses who work with palliative care patients have been specially trained, but this does not seem the case for most. Well-trained nurses often belong to specialized multidisciplinary teams found only in a few healthcare institutions and palliative care hospices.

The preliminary results of a research project entitled *Description des stresseurs et des conditions facilitantes liés à l'exercice infirmier en services de soins palliatifs, auprès de personnes atteintes de cancer, dans le contexte du virage ambulatoire*<sup>18</sup> shed light on the daily “stress factors” of palliative nursing. In hospitals and in CLSCs that do not offer organized palliative services, there is a marked lack of recognition for the valuable role nurses play. Among the major issues identified as organizational “stressors” were lack of acknowledgment for nurses with special expertise in the field, lack of communication and cooperation between units and shifts, lack of coordination between establishments, excessive workload, ambiguity of caregiver roles, lack of resources, and lack of institutional support and participation in administrative decisions.

Lastly, problems with recruiting and retaining nursing staff have been observed in hospices. This situation can be explained as much by the lack of nurses throughout the healthcare network as by the non-competitive salaries.

### *Pharmaceutical services*

Pharmaceutical expertise and the use of medications are of key importance to alleviating symptoms and pain at the end of life. A proper pharmaceutical approach is therefore crucial to offer quality palliative services to patients at home and in institutions. The main observations regarding pharmaceutical services are as follows:

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<sup>18</sup> FILLION, L., *et al.*, *op. cit.*



In institutions:

- Pharmacists are absent from most interdisciplinary teams—when they do exist—because of the complexity of their role and an organizational culture that puts the priority on curative care.
- Pharmacists are not sufficiently consulted by physicians—specialists in particular—especially when patients are still receiving curative care.
- Patients are dispersed throughout several care units, which hinders interdisciplinary teamwork and dilutes expertise.
- Pharmacists devote little time to planning for patient release and follow-up after their transfer to another institution or their return to the community, and assume that proper follow-up will be provided by teams in place, if they exist, or by community pharmacists.
- Numerous pharmacists do not have enough training on the special nature of palliative care, and there are no reference manuals to aid them.

At home:

- Pharmaceutical services are hard to access, even in urban centers, especially outside pharmacy business hours, which delays pain relief unduly.
- Attending physicians are hard to reach at all hours to adjust medication as needed.
- Pharmacists must often cover the costs for patients who do not have the equipment needed to administer medication.
- Because of competition, pharmacists fail to cooperate to ensure appropriate coverage, and there is no network of pharmacies with palliative care expertise.
- Demand is low for certain medications that are costly to prepare (i.e., under a flow hood) or require a quick turnover.
- The relationship between community pharmacists and those in CLSCs and other healthcare institutions is too weak to ensure service continuity and ensure CLSCs have the minimum supplies and pre-measured doses they need, especially on weekends.
- Pharmacists are absent from interdisciplinary teams in CLSCs.

- Managing narcotics and recovering unused medication creates problems.
- Salaries are low, which discourages night shift work.
- Medications are not suitable for children.

### *Psychosocial services*

Various experts help patients adjust to the social and emotional consequences of disease.

This includes social workers, whose role is to guide and support patients and their families. However, the special expertise palliative patients require is not truly acknowledged. Social workers refer patients to diverse professional, community, and volunteer resources. They are generally part of core caregiving teams.

It also includes psychologists, who are rather rare in the Québec palliative care network. The few psychologists in the network are part of specialized interdisciplinary palliative teams in the care units of short term care centers and university medical centers. They are virtually absent from CHSLDs, palliative care hospices, and interdisciplinary CLSC teams. The very limited range of palliative psychological services and low salaries cast real doubt on their long term future.

### *Assistance and support services*

Client care attendants work on teams in short and long term care centers, similar to family and social services assistants on CLSC homecare support teams. They are also present in numerous palliative care hospices. Such attendants provide basic care, attend to daily tasks, and ensure the comfort, wellbeing, safety, and mobility of residents. They generally receive little training.

Family and social services assistants generally work on interdisciplinary CLSC teams and provide services in the community. They visit patients and their families at home, under the supervision of professionals. They also play an educational and support role and observe, listen, and provide interim assistance with domestic matters.

### **4.3.2 Volunteers and Community Organizations**

Volunteers and community organizations have contributed immeasurably to the development of palliative care. Québec has thousands of volunteers in this area, which is one of its greatest strengths. They work with patients and their families as well as perform various administrative and technical tasks within institutions. They are employed in numerous healthcare establishments and in palliative care hospices and community organizations. They are invaluable in a support and assistance role. They generally support the staff, providing comfort and hygienic care as part of dedicated teams. In addition to their social value, volunteers are also a significant economic force.

Community organizations are key players in volunteer work. However, they are scarcer in some regions of Québec. Their existence depends on the goodwill of the community. These organizations generally focus on offering care and support to patients, listening to their concerns, and aiding families with the grieving process. Some offer respite care and ad hoc assistance, supplement the healthcare system by loaning equipment, provide transportation, make friendly visits, as well as run errands and deliver meals. Healthcare professionals and the public know little about the services community organizations provide. Even when they are familiar with their services, professionals often hesitate to refer sick people to them for fear that their services will not meet established standards of quality.

### **4.4 Interdisciplinary Palliative Care Teams**

Québec has few interdisciplinary palliative care teams. They are generally found in specialized hospital units and in palliative care hospices, especially those that serve clientele in university regions and those located on the outskirts of these regions. There are a few in CLSCs and CHSLDs, but this is the exception.

### **4.5 Access to Palliative Care Beds**

Access to beds in palliative care institutions and hospices is subject to eligibility criteria generally based on survival prognosis. Most require a prognosis of less than two months for a patient to meet their organizational standards. They suggest that the significant loss of autonomy experienced by pre-terminal and terminal patients whose death is slower in coming is not taken into account. When patients appear to require or have required more care than originally anticipated, they come under undue pressure at the end of their lives for not dying “as expected.” They feel rejected at the very time they most depend on others. This situation requires special attention.

#### **4.6 Coordinating Palliative Care Services**

One of the current problems with the palliative care system is a lack of coordination. A few regions have put together coordination committees bringing together the main palliative care stakeholders to plan comprehensive services for the entire region. Even so, all regions suffer from a lack of mechanisms to refer and direct patients in a timely fashion to palliative care services and to coordinate relations between stakeholders. This can lead to dramatic situations where patients and their families do not receive the services they need, when they need them. In certain cases, patients may feel abandoned by the healthcare system.

The lack of coordination also multiplies or intensifies patient care requirements or, on the contrary, creates large gaps in care continuity. It also leads to communication breakdowns and a lack of patient and family follow-up. Moreover, it leads to a fragmentation of services. Lastly, it increases the use of curative services (emergency room, lab, etc.) and thereby increases healthcare costs.

## **5. Guiding Principles of the Policy**



## 5. Guiding Principles of the Policy

The development of palliative care must be founded on basic principles that all health and social service network partners share. These principles underpin the partnership with patients, families, and caregivers in the planning and delivery of services. They serve as guidelines to define orientations and measures, as set out in Chapter 6. Lastly, they enable us to take a stand on certain issues, make choices, and, in short, determine how we will address the organization of palliative care in Québec.

The principles are as follows:

- **Patient needs and choices: Crucial to planning, organizing, and providing services**
- **Keeping patients in their home environment: The best option for those who so choose**
- **Supporting families: Crucial to planning, organizing, and providing services**

### 5.1 Patient Needs and Choices: Crucial to Planning, Organizing, and Providing Services

In palliative care, regardless of the institution, all decisions regarding planning, organizing, and providing services must put patient needs and choices first. The **following conditions** must be respected to tailor services to patients and their environment:

- Patients must participate in all decisions concerning them. To make informed choices, they must be clearly informed as to their condition and the various options open to them.
- Services must be planned and provided in accordance with the values of patients and their families.
- Services must be aimed at maintaining the best quality of life possible for patients and their families, while respecting patient dignity and privacy. In this respect, there should be no more caregivers from the same field as are necessary to care for patients.
- The complexity of accessing the health and social services system must be assumed by healthcare network planners and suppliers, and not by patients and their families.

## 5.2 Keeping Patients in Their Home Environment: The Best Option for Those Who So Choose

This policy favors providing services as close as possible to the patient's natural living environment, namely his or her home.<sup>19</sup>

It therefore makes developing frontline services a priority to keep patients who so desire and whose condition so allows in their home environment as long as possible. Families must be taken into account in this decision and receive the necessary support. The patient's environment is another aspect to consider.

As much as possible, homecare support must always be the first choice. It must no longer be seen as a simple alternative to placement or hospitalization. This philosophy also applies to palliative care. It is especially appropriate given that a large number of patients would prefer to stay at home as long as possible if they could be sure they would receive proper care and not be a burden on their families.<sup>20</sup> **Fundamental criteria** must be met to make this option a reality:

- Services must be available when they are needed, without patients and their families having to wait.
- A full spectrum of services must be available at all stages of the patient's disease.
- Patients must be able to reverse their decision to stay at home and to substitute other community resources they believe are better suited to their needs.

These criteria are crucial. Without them, quality homecare services cannot be ensured. For people to be able to choose to spend their last days at home or support a patient in their home environment, the care provided must meet the needs of patients at all times.

In addition, services must be flexible to adjust to sudden changes in the patient's condition. The components of necessary services are described below.

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<sup>19</sup> Home refers to the usual place of residence: House or private lodging, low-cost housing, retirement home, room and board.

<sup>20</sup> Senate Standing Committee on Social Affairs, Science and Technology. *"Of Life and Death," Quality End-of-Life Care: The Right of Every Canadian*, (subcommittee report), 1995.



### 5.3 Supporting Families: Crucial to Planning, Organizing, and Providing Services

The participation of families is often crucial<sup>21</sup> in palliative care. It can play a key role in the quality and intensity of patient services. However, such a commitment often entails heavy responsibilities for people grappling with the illness and imminent death of a loved one, for others who may have health problems themselves, or for others still who are simply struggling to make a living.

Support for families is aimed at preserving their ability to maintain a relationship with the patient. To accomplish this, families must be **seen in two ways**.

#### *As clients first*

Given this unique context, service providers must see families first as clients who need support and guidance at a difficult time. This support can take diverse forms: information, psychological aid, domestic help, respite care, an attentive ear, temporary away-from-home care, grief counseling, etc.

#### *As people who can also play a role in care*

The participation of families in caregiving must remain voluntary and take into account their abilities. If families agree to get involved, certain **criteria must be met** to enable them to carry out their duties to the fullest. They must...

- Have all the information they need (clinical and other) on the patient's condition, with his or her prior consent
- Master the necessary caregiving techniques, which requires supervised training and hands-on experience
- Know who to call in case of emergency and for immediate assistance
- Be able to gauge when certain tasks become too demanding and leave them to health and social services workers

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<sup>21</sup> However, we must remember the isolation of some—namely the elderly—who cannot rely on their families. This phenomenon is especially pronounced in large urban centers such as Montréal.



## **6. Main Goals of the Policy**



## **6. Main Goals of the Policy**

This palliative care policy has the following four main goals:

- 1. Ensure fair access to services across Québec**
- 2. Ensure service continuity throughout the healthcare system**
- 3. Ensure the quality of services provided by interdisciplinary teams**
- 4. Raise awareness among caregivers of the inescapable nature of death**

### **6.1 First Main Goal: Ensure Fair Access to Services Across Québec**

This main goal raises numerous issues. It involves the various palliative care settings and the services each of them offer patients and their families.

In accordance with the ideas of accessibility and fairness, services must be available in each region of Québec so that all those who require them receive the proper care close to home. As much as possible, people should be able to choose the facilities where they are cared for.

To ensure fair access to services, some measures and initiatives are necessary:

- A. Enhance, diversify, and standardize the array of basic public palliative care services to take into account their complexity, diversity, and intensity**
- B. Recognize the need for a interdisciplinary team to serve patients at each location**
- C. Inform the public, patients, families, and healthcare professionals about existing services**
- D. Define and standardize the terms and criteria for receiving palliative care**
- E. Define and standardize patients' financial contribution**

## **A. Enhance, Diversify, and Standardize the Array of Basic Public Palliative Care Services to Take Into Account Their Complexity, Diversity, and Intensity**

Though this policy does not seek to make all services perfectly the same, by definition fair access implies a certain uniformity in the services available. In addition, the intensity of services requires that some of them—such as nursing care and support services—be available on an ongoing basis, 24 hours a day, 7 days a week.

**The following services must be available regardless of pathology, age, or social status:**

### **1) Regular CLSC services provided onsite<sup>22</sup>**

- Health and social services
- Nursing care and psychosocial services

### **2) Homecare support services**

*Basic services provided by interdisciplinary team members*

- 24-hour-a-day, 7-day-a-week medical services (home visits and phone helpline) provided by family medicine group (FMG) physicians, CLSC physicians, medical clinic physicians, and hospital physicians who provide at-home follow-up
- Ongoing CLSC (or local agency) nursing care 24 hours a day, 7 days a week
- CLSC psychosocial services (social workers and psychologists) to support patients and families in the community for as long as necessary, including systematic psychological support for patients, families, and children prior to and during normal grieving, to prevent pathological grief
- CLSC occupational therapy, physiotherapy, and nutrition services
- CLSC homecare support services such as personal assistance and domestic help
- CLSC homecare respite, temporary away-from-home care, and elder sitting services

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<sup>22</sup> If patients and families are mobile.

- 24-hour-a-day, 7-day-a-week phone services providing vulnerable clientele with a quick response and swift access to a clinician trained to meet the special needs of palliative patients
- 24-hour-a-day, 7-day-a-week pharmaceutical support by community and healthcare facility pharmacists who have signed agreements to monitor patients outside of pharmacy business hours
- Equipment, including remote monitoring equipment, technical aids, and medical supplies

*Complementary services on an as-needed basis*

- Spiritual counseling, regardless of denomination or religious status. CLSCs and local service network development agencies must work together to plan these services, in conjunction with religious authorities if need be
- Support activities, such as help with drawing up a will and power of attorney, and abuse prevention activities provided by CLSC social workers
- Meal preparation and patient support by caregiver organizations, associations, and volunteers of all origins
- Patient transportation

### **3) Day Center Services**

These services focus on improving patient wellbeing (therapeutic baths, additional baths, etc.) and providing opportunities to socialize. They enable patients to stay in touch with the community by stimulating them and breaking their isolation. Patients who use these services must be mobile. For families, these services are a respite resource that frees them to take care of other social and family obligations.

Day center services complement homecare services. They may be provided at CHSLDs, palliative care hospices, or CLSCs.

Day center staff must have a good understanding of the palliative approach.

Lastly, these services are available to patients who wish to use them, but are not designed to make up for deficient homecare services.

#### **4) Respite Services and Temporary Away-From-Home Care**

These services help maintain the commitment of families to patients when unexpected circumstances arise or when they need a break. Respite services let families rest, which reduces the stress and fatigue they feel because of their emotional involvement and the help they provide patients. They also enable families to meet their other family and social obligations.

Though the services provided in substitute<sup>23</sup> settings give families a respite, they must meet patient needs, based on their current medical condition.

When the medical condition of patients is more or less stable, these services can be offered in CHSLDs and palliative hospices.

When their condition is unstable or requires special equipment, patients will be referred to palliative care units, other hospitals with an interdisciplinary palliative care team, or palliative hospices capable of providing the necessary services.

These facilities provide round-the-clock medical, nursing, and pharmaceutical services to meet patient needs. Staff who know the patients and their families provide them with psychosocial services. To achieve this goal, CLSC social workers or psychologists must, as much as possible, continue to provide psychosocial follow-up of temporary patients. Other complementary services—notably to meet spiritual needs—must also be available.

#### **5) Services Provided as Part of Special Palliative Care Programs**

These services are designed for non-autonomous patients with diseases that are progressing slowly and are fatal in the medium to long term, and who are already in long term care centers (CHSLDs). Some of these patients need palliative care upon arrival, as their health dictates that they seek to maintain quality of life rather than achieve a cure.

This policy does not encourage the creation of specialized palliative care units or beds for permanent facility residents. It is preferable that residents receive services in their usual unit, while having access to special programs. However, in the case of terminal patients, the environment must meet their and their families' need for privacy. At the same time, the right of other patients to their privacy must also be respected.

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<sup>23</sup> Substitute settings are caregiving facilities other than the usual place of residence.



The goals of palliative care programs are as follows:

- Provide care as required in accordance with established standards, taking a holistic approach to patient wellbeing that is respectful of his or her dignity
- Support families in the process leading up to the loss of a loved one and refer them to community services for assistance with normal or pathological grief

These programs have workers trained in palliative care. Their duties are to support care unit staff as they serve patients and their families. They must also train staff on the palliative approach. These workers must have the time they need to fulfill their duties.

These programs are also for incapable people, including those represented by the Public Curator. It is important to keep them in their home environment, whether it is a CHSLD, interim resource, or family-based resource.

## **6) Services Provided by Palliative Care Hospices**

The use of palliative care hospices is up to regions, provided the hospices meet the criteria described below. As well, the mandate of existing hospices can be carried over if their activities dovetail with overall regional planning measures.

### *Overall regional planning*

To ensure hospices meet overall regional planning goals, measures are needed to prevent *de facto* situations where the hospice is already built and finished and a fundraising campaign has already raised some of the operating costs. A mechanism involving promoters, local service network development agencies, MSSS, and the Régistraire des entreprises du Québec (REQ) will be developed to ensure these projects fit with overall regional planning goals.

Moreover, to ensure that the services provided by hospices fit with and complement those provided by other facilities in the area (hospitals, CLSCs, CHSLDs, etc.), all hospices must sign formal agreements with one or more local service providers. These agreements are to ensure the delivery of services not available at the hospice. The clinical services that patients and their families need and that hospices cannot provide with their own staff will be provided through a partnership agreement with one or more institutions, FMG or private practice physicians, and community pharmacists.

### *Clientele characteristics*

From now on, in accordance with usual admission criteria, hospices must accept patients regardless of age, pathology, or income if their home support is inadequate, if their condition and the intensity of care they require (constant monitoring 24 hours a day, 7 days a week) means they can no longer stay at home, or if they wish to continue their care in this type of environment.

Accepting patients regardless of their characteristics will require major changes to current practices, whereby hospices generally only accept terminal phase adult cancer patients. This poses a challenge that hospices must meet progressively under the watchful eye of local service network development agencies.

### *Service goals*

The goals of specialized hospice services are as follows:

- Provide ongoing clinical services in accordance with established standards through an overall approach that meets patients' physical, psychological, spiritual, and cultural needs
- Provide patients with room and board and the necessary support
- Prepare families for bereavement and refer them to community services for normal or pathological grief

### *Criteria for planners and administrators*

However, given these goals, planners and administrators must meet the following **essential criteria**:

- Their activities must comply with laws and regulations in force, including the *Act respecting health service and social services*.
- Corporations that operate palliative care hospices must be non-profit, legally constituted entities.
- Hospices must be duly accredited by an authorized organization (timeframe pending).
- Clinical services must meet established healthcare norms and standards (timeframe pending) and be provided by well-trained palliative staff and volunteers to ensure as much as possible that patients and families deal mainly with a core group of caregivers.

- Nursing and patient support services must be provided on an ongoing basis, 24 hours a day, 7 days a week.
- The physical environment and services available must meet children’s needs and also meet pediatric standards (timeframe and standards pending). Pediatric expertise must be available by establishing ties with experts in public institutions.
- Room and board as well as support services must meet palliative care quality norms and standards.

Certain special aspects must be governed by hospice protocols or policies. Accordingly, they must draw up...

- A code of ethics
- A case management policy
- A narcotics management protocol
- A biomedical waste management policy
- An ambulance transport protocol
- A complaint investigation process
- A volunteer training policy
- An accountability process

Subject to the approval of MSSS and local service network development agencies, hospices may partner with universities to develop a teaching and research function, which will broaden their role beyond their region.

## **7) Services Provided by Palliative Care Units**

Patients whose health necessitates ongoing nursing care and specialized facilities must have access—regardless of age or disease—to a palliative care unit with beds grouped together in a given region, according to pending criteria.<sup>24</sup> These units can be in specialized institutions (hospitals<sup>25</sup> and CHSLDs). They accept patients whose health requires specialized expertise.

<sup>24</sup> Access criteria will be determined based on a beds/deaths ratio, distance (90 kilometers), and travel time (60 minutes).

<sup>25</sup> In the Québec City region, the private hospital Maison Michel-Sarrazin is considered a palliative care unit.

These services cannot be provided at home, in certain CHSLDs and hospices, or in hospitals without a palliative unit.

The goals of these services are as follows:

- Stabilize patients' condition by adjusting medication to alleviate symptoms and pain before their return to the community, health permitting
- Temporarily or permanently accommodate patients whose poor health does not allow them to stay in the community or who wish to continue in this type of setting in the terminal stage, in keeping with the main mission of these units
- Provide holistic care through an interdisciplinary team to meet patients' physical, psychological, and spiritual needs
- Support caregivers in other care units through advice and direct involvement with patients and their families as needed
- Upon their request, support frontline caregivers through advice and training or regular contact with patients and families
- Support families in the process leading up to the loss of a loved one and refer them to community services for help with normal or pathological grief

#### **8) Services Provided by Hospitals Without Palliative Units**

All hospitals that do not have palliative units must provide on-site services through an interdisciplinary team (see Criterion B).

#### **9) Research and Training Programs**

Regardless of services and service providers, patients and their families must enjoy the benefit of research and training programs. These programs are handled by centers of excellence in palliative care, in cooperation with universities. They exist for all types of services.

These institutions must become palliative care research leaders in the control of symptoms and pain as well as grief counseling. They provide a setting to experiment with new ways of organizing and providing care based on interdisciplinary teamwork and cooperation between partners from various sectors.

The Québec government, in cooperation with its education and health and social services partners, must develop a network of researchers from these centers. The goal is to create a veritable synergy between researchers and maximize results in a cost-effective manner.

These centers also provide leading-edge palliative training and ways to acquire and share this knowledge. Their expertise must be made available to other institutions right across Québec with which they have close and complementary relations.

Institutions must create an environment conducive to research and training and take concrete steps to make room for these activities: special budgets, technical support, clerical staff, work space suited to their requirements and available at all times, etc.

## **B. Recognize the Need for an Interdisciplinary Team to Serve Patients**

The palliative approach requires caregivers to share all knowledge on the patient's physical and psychological health to optimize care aimed at improving quality of life. This sharing of knowledge presupposes interdisciplinary involvement. A shared vision heightens the efficiency and effectiveness of services. It also increases staff's sense of belonging.

Patients and their families have multiple, complex needs. Taking these needs fully into account requires ongoing cooperation from all qualified caregivers. This cooperation must serve to develop and implement a service plan<sup>26</sup> in the form of an intervention plan (IP) or individualized service plan (ISP) if the plan involves more than one institution. With respect to ISPs, they further require an intervention plan for each service provider.

This service plan must be flexible and personalized. It should be updated regularly to take into account the changing needs of patients and families, particularly in the terminal phase. It must leave ample room for patient input and recognize the role of significant people in the patient's life, if he or she so desires. The plan must also take into account the patient's values and beliefs while also respecting the patient's privacy and dignity.

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<sup>26</sup> As stipulated by the *Act respecting health services and social services*, sections 102 and 103

Teamwork provides each member with mutual support when discussing problems and making crucial decisions. It also lets them share their feelings about this very unique situation with their colleagues. In short, it lightens the burden of certain aspects of clinical practice, such as ethical decisions.

Members of the caregiving team in the curative phase may also be involved in the palliative phase, notably in oncology. Close ties must exist between the teams. Information on how to ensure this is provided in the section on service continuity.

*Develop an interdisciplinary team at each care facility*

Each care facility defined in the section above (6A) must have a caregiving team with palliative care expertise. In addition to serving patients itself, the team offers its expertise to staff in various programs or health units to help them serve pre-terminal and terminal patients and their families. These services are provided regardless of patient age or pathology. For an illustration of the relationship between this team and the caregiving team from the active treatment phase, see the case study of an end-of-life cancer patient at the end of this document.

Interdisciplinary teams have the following goals:

- Evaluate and stabilize patient health, control symptoms and pain, and provide services in various caregiving settings and through the various programs of each facility using an overall approach to patient care that meets their physical, psychological, and spiritual needs
- Support caregivers in other care settings through training, advice, and, as needed, direct contact with patients and their families
- Support families in the process leading up to the loss of a loved one and refer them to community services for help with normal or pathological grief

These teams are composed of the following people: physicians, pharmacists, nurses, social workers, psychologists, pastoral associates, nutritionists, occupational therapists, physiotherapists, and any other expert with the skills needed to meet intervention plan goals. Specialists or family physicians that have already treated patients may advise or be part of the team. Community resources and volunteers provide further support to these teams if patients so desire, while respecting the privacy of patients.

Pastoral associates are employed by institutions as the pastoral representative of their religious authority, as set out in the memorandum of understanding between MSSS and the main denominational authorities as well as the terms of reference on the organization of pastoral services in healthcare settings.

The creation of a local authority combining numerous types of institutions (hospitals, CHSLDs, CLSCs) into a local service network will enhance pastoral associates' availability in the home environment. Members of homecare support teams should be able to count on a qualified resource to help them address spiritual needs.

*Develop an interdisciplinary team to serve a supraregional role*

A supraregional interdisciplinary clinical team must be developed to support caregivers across Québec, particularly in intermediate and remote regions. This team will include specialists from recognized palliative fields with cutting-edge expertise and ties to universities. Representatives from each category of service provider will be part of this team. The professional makeup of the supraregional team must be the same as for teams in other care settings.

This team will be particularly useful for complex cases and special needs clientele. It will be available on request to interdisciplinary teams in a region if the region cannot meet patient needs.

This support measure will use flexible communication methods (telephone, email, etc.) to forward all necessary information, in real time if need be.

Team setup will be arranged by MSSS in cooperation with institutional associations, development agencies, training centers, and professional bodies.

**C. Inform the Public, Patients, Families, and Healthcare Professionals About Existing Services**

Other major factors than interdisciplinary services and teams have an impact on fair access to palliative care.

The general public and people directly involved know little about palliative care. Even healthcare professionals and frontline physicians, who patients and families see as experts, are not always up-to-date on available regional resources. This is an obvious roadblock to timely palliative care referral.

Caregivers must be able to provide patients and families with clear advice on their options to help them make informed choices. This is even more important in palliative care because it involves determining the best place to spend—either full or part time—one’s final days.

Moreover, service providers, given their perceived lack of resources and the high demand for their services, do not always want to explain or seek to explain their services to the public. They just try to do their best to meet demand. This attitude leads to unfairness, and the main victims are those who are less capable or less well informed, often because of unfavorable socioeconomic conditions or cognitive disabilities.

To encourage fair access, equivalent services must be provided, combined with better information for the public and caregivers. In this respect, MSSS has a key role to play in cooperation with local service network development agencies and service providers.

Information must be conveyed to the public in plain language to inform citizens of their rights and the services available. For example, a brochure on palliative care would be a good way to inform people in each region.

#### **D. Define and Standardize the Terms and Criteria for Receiving Palliative Care**

To ensure fair access, program and service eligibility criteria must be clearly defined and standardized for similar facilities. Regardless of region, hospitals should also adopt similar criteria. The same applies to homecare support services and other programs or facilities.

There is still much to do in this regard, particularly with respect to palliative homecare, whose development has been left to the discretion of local or regional authorities.

Moreover, service access criteria must be based on an evaluation by healthcare professionals of patient and family needs. These criteria must be applied humanely. Admission systems based solely on administrative criteria such as survival prognosis must be reviewed. Moreover, proven and standardized evaluation tools such as the multiclientele tool must be used to enhance professional judgment, not replace it.



## **E. Define and Standardize Patients' Financial Contribution**

Fair access also means that patients pay the same from one region and area to the next for services from the same type of provider (CLSC, CHSLD, hospital, hospice, etc.).

With the exception of medication, the cost to the patient should be the same no matter where treatment is provided—at home or in a hospital. Obviously, this will never be absolute, as patients who stay at home pay living expenses they would not have incurred in a hospital, such as the cost of meals.

Moreover, publicly funded service providers must not charge patients fees or require payment, including for homecare services.

Homecare equipment, supplies, and technical aids must be available without patient contribution. Patients should also never have to cover their shipping or installation costs. In terms of home adaptation, which Société d'habitation du Québec oversees, any services provided must be timely from a patient prognosis perspective.

In terms of hospitals and CHSLDs, any adjustments needed to provide end-of-life care (private room, additional nursing staff, etc.) must not create additional expenses for patients.

With respect to palliative hospices, patients cannot be charged for any healthcare services they receive, even at night.

For temporary accommodation at an institution, MSSS has standard rates that cover the cost of room and board.

In day centers, patient contribution may only equal meal expenses.

Patients may not be charged for ambulance transportation, regardless of their age or geographic location.

## **6.2 Second Main Goal: Ensure Continuity Between Facilities**

Numerous organizations are involved in providing palliative care. Patients' condition can change very quickly, from the moment a potentially fatal disease is diagnosed up until death. Patients and families therefore have diverse, complex needs that require quick, personalized answers. Many service providers will get involved at various stages, whether in the home environment or an institution.

We must therefore do our utmost to ensure that service providers are the ones who shoulder the healthcare system's complexity. End-of-life patients and their families, who are at the whole reason for the process, must not perceive or bear the burden of this complexity.

The circulation of information, access to timely expertise in the proper setting, and immediate access to medications and supplies are challenges that the Québec health system must meet, particularly for palliative care. Service continuity must be an overarching concern.

This policy is aimed at reaffirming that service continuity is a fundamental priority and that no effort must be spared to make it a reality. Service continuity requires ongoing cooperation and collaboration at all levels between service providers.

To ensure service continuity, regional and territorial organizational choices must take into account community resources. In most cases, these choices will be the responsibility of local service networks, which will oversee the organization of services in their regions in cooperation with the community.

The following **measures and criteria** are crucial to ensure service continuity:

- A. Clearly define the responsibilities of all palliative care providers**
- B. Develop a mechanism for regional cooperation between service managers**
- C. Develop measures to ensure continuity between palliative care providers**

#### **A. Clearly Define the Responsibilities of All Palliative Care Providers**

Under this policy and the supervision of local service network development agencies, each service provider must clearly define its responsibilities for providing palliative care in a given region to eliminate any confusion in patient intake, and must devote the necessary resources to the task. Definitions must include the notion of complementarity.

This clarification of territorial responsibilities must include all necessary palliative services, as defined in Section 6.1.

## **B. Develop a Mechanism for Regional Cooperation Between Service Managers**

In addition to a clear division of responsibilities, rigorous cooperation measures must be put in place to ensure service continuity, from the diagnosis of an incurable disease up until death.

Under the supervision of local health and social service network development agencies, managers must develop an ongoing cooperation committee to harmonize and integrate services between service providers. This committee will collect feedback from interdisciplinary teams on the various problems they encounter, with a view to helping managers update at least yearly a service cooperation and continuity model intended to guarantee service effectiveness.

Each service provider must be represented by a manager with the authority to solve problems quickly. This is the manager who will report to the local health and social service network development agency on his organization's performance. Supraregional institutions are accountable to MSSS.

Managers must regularly ensure their organizations run smoothly within this model and, as needed, make adjustments so that services are provided in accordance with it.

## **C. Develop Measures to Ensure Continuity Between Service Providers**

Measures must be developed to ensure service continuity, from the diagnosis of an incurable disease up until patient death.

*Develop a systematic referral system for community palliative care services*

Referrals must come early in the process if patients are to benefit from community-based services and overall palliative care. Once the diagnosis is known, service providers must offer patients support and refer them—with their consent—to the CLSC in their area. They must also leave an information leaflet on the procedure to follow.

Service providers (hospitals, outpatient clinics, emergency rooms, medical clinics, etc.) are the ones that suggest this option, make the necessary contacts, and refer patients to the appropriate resources. Any important information is forwarded to the CLSC by the caregiving team coordinator (or liaison officer) to ensure mutual understanding. This process in no way releases service providers from their obligation to properly support patients when their diagnosis is announced to them.

At this stage, community referrals can give patients the help they need to preserve or restore their self-worth. In addition, immediately establishing ties with community resources will later smooth the transition to a home environment if the progression of the disease has made palliative measures necessary.

If the condition of patients worsens and curative therapies have failed, they are alerted to the palliative approach in a timely manner and the options it provides to them and their families. To this end, their situation is brought to the attention of the person responsible<sup>27</sup> for coordinating palliative care in the community (see following section). Patients are contacted within 24 hours and quickly meet with a CLSC representative to assess their needs in detail and obtain the services they require. Patients enjoy personalized attention at all times.

However, in reality it is not always easy to identify or recognize patients in the pre-terminal or terminal phase of a disease. Certain **criteria and measures** must therefore be drawn up for service providers, namely

- A teamwork approach for patients with serious diseases (cancer, heart disease, chronic pulmonary obstructive disease, etc.) to more easily identify patients likely to benefit from palliative care
- Guidelines on managing the transition from curative to palliative care and on palliative care referral criteria

All those involved in caring for patients with a serious disease should meet regularly to share information in order to better gauge when palliative care becomes necessary. These people should have frequent contact with palliative care teams. These meetings should be held on an institutional, territorial, or regional level, depending on regional realities.

#### *Assign a territorial service coordinator*

So that patients always have someone to turn to upon diagnosis of an incurable disease, each local service network must assign a healthcare professional to coordinate palliative care. This person is to take the complexity out of the system for patients and families and ensure they get the services they require based on their needs and choices. He or she must liaise with all regional organizations and be very familiar with the patient's case as well as community organizations and resources. He or she must also have maintained close ties with the patient's caregiving team in the curative phase—notably in oncology—and may seek the assistance of this team as needed.

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<sup>27</sup> Patients and families may also contact CLSCs themselves.

This coordinator must have a clear, universally understood mandate with the appropriate powers to open all doors without undue delay. In case of problems, he or she may contact the regional cooperation committee (B).

The profession of the person (nurse or social worker) in this key position is less important than his or her expertise and acceptance by the community. Since this policy stresses keeping patients in their home environment, for administrative purposes the coordinator should report to the CLSC.

The coordinator need not be associated exclusively with palliative care. Measures to ensure service continuity already exist. It is important to strengthen these measures, as death is the final stage in a process that often begins much earlier in the healthcare system.

*Involve physicians and pharmacists in the process as indispensable partners*

Continuity in care cannot be ensured without the full and wholehearted cooperation of all caregivers. Physicians and pharmacists are crucial in palliative care to reassure patients, families, and other caregivers, while supporting coordinators.

Ideally, each patient should have a family physician to provide medical follow-up in cooperation with the attending physician, who may change at various times depending on the progression of the disease. Family physicians are the ones who coordinate medical referrals for patients and bring the coordinator into the picture. They may be assisted in this task by a nurse if they belong to an FMG or other type of organization with such a resource.

In the palliative phase, 24 hour access to physicians and medication, regardless of the patient's location, creates difficulties that all palliative resources must work together to overcome (FMG, medical clinics, CLSC physicians, 24/7 sitter, community and hospital pharmacists, etc.). The challenge is particularly great outside of hospitals, especially in the evening, at night, and on weekends. Round-the-clock access to physicians and medication is nonetheless vital to success.

Homecare staff must also have access to physicians for advice and to adjust medication as needed. Regional departments of general medicine (DRMG) are responsible for organizing medical services in each region.

Medication must be immediately available through community or hospital pharmacists or CLSCs, where qualified staff can dispense preprepared medications according to established rules. The management and administration of narcotics, including recovering unused medications, must be governed by very clear protocols. Lastly, CLSCs must cover the costs of supplies needed to administer medications to homecare patients (e.g., patient-controlled morphine pumps).

#### *Ensure referral quality*

Referral measures to smooth the transition between facilities are also of key importance in palliative care. Patients with an incurable disease who, for example, receive homecare services after leaving the hospital must be provided with ongoing support. Service providers must look after the details of transfers from one setting to another to reassure patients and families as much as possible. Service providers that refer patients to another resource are responsible for ensuring service continuity.

Referrals must make it easy to forward personal and clinical patient information so that the new service provider can quickly provide services. Patients and families must also have all the information and knowledge they need to feel comfortable with what comes next. This means, among other things, that they have the name and number of the person (or his or her replacement, 24 hours a day, 7 days a week) who will coordinate clinical care.

#### *Develop effective communication methods*

Efficient circulation of information among healthcare professionals is a prerequisite for service continuity. Caregivers must have confidential, real-time access to all the information they require on the patient's condition.

Healthcare professionals must also be able to communicate easily among themselves to forward the clinical information, advice, and prescriptions patients need. The teamwork inherent to quality palliative care requires excellent communication between caregivers from various fields of expertise. With respect to homecare patients, it is important that caregivers have real-time access to clinical information (health status, medication changes, etc.) through electronic means or access to the file at home.

Many tools already exist to forward this information. In this respect, the health access card will no doubt prove useful. In summary, it is important for palliative care to reap maximum benefit from new information technologies.

### **6.3 Third Main Goal: Ensure the Quality of Services Provided by Interdisciplinary Teams**

Service quality is a very broad concept that encompasses many issues. It must be found at each stage of the caregiving process: evaluation, diagnosis and prognosis, decision, referral, orientation, care planning, service acceptance, caregiving, grief counseling. Both communication and the clinical quality of services provided to alleviate the physical and moral suffering of patients and families and help maintain quality of life are part of service quality.

Other services are also part of it, such as hospital care (cleanliness, suitability, and comfort), meals (food safety and quality), hygienic care (frequency and respect for privacy), domestic help, notice of death, removal of body, etc. The quality of palliative care therefore also depends on factors that are not strictly clinical.

Accessibility and continuity are key to service quality. These factors were discussed in more detail in the two previous sections. Here, improving service quality refers mostly to clinical intervention and other direct services for patients and families.

This policy makes improving the quality of palliative care a fundamental priority. Our success in doing so will depend on the following criteria and measures:

- A. Design and implement practice standards and protocols**
- B. Improve basic and professional training for all those in contact with patients and families**
- C. Put in place a program evaluation tool that includes a quality evaluation system**
- D. Foster R&D**

#### **A. Design and Implement Practice Standards and Protocols**

Practice standards help guide palliative care practitioners on how to deal with a given situation. They serve as guidelines in developing service plans and help standardize practices. Because they are developed by palliative care experts who have pooled their knowledge and experience, these standards ensure quality improvement. They also provide an ideal clinical and organizational frame of reference.

Under the supervision of development agencies, each palliative care service provider must implement recognized standards of practice in their field. In this respect, they can draw on the standards developed by Réseau de soins palliatifs du Québec or included in the Canadian Hospice Palliative Care Association guide.<sup>28</sup> This promising guide, which was developed in cooperation with provincial associations, discusses all practical aspects of palliative care.

MSSS must support the development and implementation of new standards of practice for each palliative care discipline, in cooperation with Réseau de soins palliatifs du Québec and professional associations. One of the priorities in this regard is to develop criteria to guide the transition from curative care to palliative care and thereby facilitate the task of clinical staff.

## **B. Improve Basic and Professional Training for All Those in Contact with Patients and Families**

The complexity of palliative care means patients and families are in contact with many kinds of healthcare professionals. These professionals must have the basic skills to provide palliative care. Volunteers must also acquire the skills and knowledge needed to care for end-of-life patients.

Professionals must therefore have received basic training that prepares them for this process or acquired skills through on-the-job or professional training. Volunteer training programs are also necessary.

Training must take into account the diverse patients that caregivers deal with: children and adolescents, people with cancer, cardiovascular diseases, diabetes, neurological diseases, etc. The goal is not to encourage overspecialization in palliative care, but to ensure caregivers have the basic knowledge for a particular clientele.

Regardless of clientele, the training provided must use standardized tools developed in cooperation with teaching institutions and health and social services network partners. Even though responsibility for network staff training was decentralized to local service network development agencies a number of years ago, MSSS must still seek to ensure that these goals are met across Québec.

Palliative care training centers must be officially accredited. The training duties of medical staff must be acknowledged and remunerated accordingly by Régie de l'assurance maladie du Québec (RAMQ). Lastly, quality training also requires quality clinical settings with the necessary facilities.

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<sup>28</sup> Canadian Hospice Palliative Care Association, *op. cit.*



Interdisciplinary teams—the supraregional team in particular—can contribute significantly to determining the training needs of various regions of Québec.

#### *Basic training*

Each university-level health sciences, pharmacy, or medicine training program must include courses and internships to deepen understanding of end-of-life patient care. University curriculums must be tailored accordingly.

There is a consensus that palliative care should not become a medical specialty. However, it is important that students and medical residents be more aware of the characteristics of end-of-life care. Moreover, the faculties of medicine of Canadian universities, including a few in Québec, already provide advanced training in palliative medicine. We can only encourage all Québec faculties of medicine to step up their efforts to adequately train future physicians to recognize when palliative care becomes necessary and provide care in accordance with this approach. Training should also develop their interest in interdisciplinary teamwork.

The same applies to training for pharmacy students, which must also help them acquire knowledge on the characteristics of palliative care, as well as for students in other disciplines such as nursing sciences (university level) or nursing techniques (college level). Secondary-level training for nursing assistants must also stress the acquisition of palliative care expertise.

In addition to their basic training, client care attendants and visiting homemakers must be provided with on-the-job training on the palliative approach, as they are in direct contact with patients.

#### *On-the-job training and professional training*

Everyone who is involved with end-of-life patients even sporadically must be properly trained. In this respect, agencies, in cooperation with institutions, will ensure the staff involved have the skills they need for this special field.

To this end, MSSS, in partnership with teaching institutions, will support local service network development agencies by helping develop training and intervention tools (courses, kits, distance learning, etc.) that incorporate the latest knowledge and teaching methods.

Caregivers who wish to hone their expertise even more and update their skills should be able to count on professional training programs in all regions of Québec. Each palliative care team should include a certain number of experienced, well-trained members. Administrators should encourage their staff to perfect their understanding of patient and family needs by allowing them to participate in discussion groups and case studies to know how to act in complex situations where ethical issues come into play.

Training programs must be tailored to the special learning needs of caregivers based on their profession and the socioeconomic and cultural characteristics of the clientele they will serve. These programs must also cover training for community pharmacists, who deal with a homecare clientele.

Training activities on the special needs of families including workshops on grief must also be organized for staff. Staff should be allowed to attend conferences, colloquiums, and seminars to update their knowledge and enable caregivers to network with others and benefit from their clinical experience.

#### *Volunteer training*

Volunteers must be provided basic training to arm them with the skills to care for the sick. They must learn to recognize their limits and work in partnership with healthcare professionals. This basic training will enable them to better complement caregiving teams.

The organization that volunteers report to is responsible for training them using standardized tools, with the support of local service network development agencies. In the case of volunteer organizations, institutions that benefit from their services must assist them in this task.

### **C. Put in Place a Program Evaluation Tool That Includes a Quality Evaluation System**

MSSS will track results to compare Québec's situation to that of other countries and Canadian provinces.

In institutions, a service quality measurement system must be developed to ensure that each service provider fulfills its duties and that the services provided meet standards and norms of quality. This system must include the measurement of patient and family satisfaction. Accreditation councils will play a role in this process.

## **D. Foster R&D**

Palliative care research is key to improving service quality. Much remains to be done in this regard, as palliative medicine is a relatively young field. In terms of research, service providers that work with universities are especially important.

The Québec government must back palliative care research and ensure that granting agencies such as Fonds de la recherche en santé du Québec (FRSQ) and Fonds de la recherche sur la société et la culture (FRSC) make palliative care a priority.

The Québec government must also back research that will facilitate implementation of this policy. It must be a partner in various research projects to ensure existing teams are competitive with all emerging research networks across Canada. It must also help bring together the leading palliative care researchers at a provincial level.

### **6.4 Fourth Main Goal: Raise Awareness Among Caregivers of the Inescapable Nature of Death**

Social attitudes towards death pose a challenge to the development of palliative care. Society tends to pretend death does not exist and people consider it a taboo, which prevents them from preparing for death unless they themselves are faced with it, whether directly or indirectly. Consequently, their expectations regarding medicine and technology can sometimes seem excessive and be a hindrance to timely palliative care. Values and attitudes towards death also influence the way caregivers provide services.

This policy therefore stresses raising awareness among caregivers of the natural and inescapable nature of death for them to better prepare patients. This process must be ongoing and tailored to the values and characteristics of Québec society.

As such, MSSS will develop with its partners an awareness strategy whose message will vary according to target audience: healthcare professionals, administrators, families, etc. Community organizations and volunteers may also be targeted.

This communication strategy will foster discussion on the meaning and values of life. It will stress human solidarity, mutual assistance, and compassion during this period of fragility and account making.

This campaign will be educational—while avoiding any moralizing on end-of-life options—and aimed at helping citizens and healthcare professionals get their bearings and know who to turn to depending on the situation.

It must also be adapted to the socioeconomic and cultural characteristics of Québec society as a whole. The approach and message must be suitable for the rites and beliefs of various cultural and aboriginal communities. It must also deal effectively with the spiritual aspect of death.

This strategy must include concrete measures to help patients, families, and caregivers make decisions based on the progression of disease. These measures will raise awareness of patient rights and help foster dialogue on end-of-life wishes. In this regard, the end-of-life instructions given by patients who are still lucid can be valuable. These instructions can make it easier for the caregiving team and families to decide when to stop treatment.

We must promote these methods that allow us to both confront our mortal condition and question our fundamental values in the face of life and death.



## **7. Special Characteristics of Pediatric Palliative Care**



## 7. Special Characteristics of Pediatric Palliative Care

In palliative care, one patient group deserves special attention: that of children, adolescents, and their families. Our society, already ill at ease with death in general, is even less comfortable dealing with the death of children and adolescents. The specific nature of their needs and those of their families warrants further investigation. The general approach recommended in this document and the proposed organizational model also apply to pediatric palliative care, but with added nuances that will be listed in this chapter. The complete version of this text and the special characteristics of pediatric palliative care are available on the MSSS website.

### *Specific characteristics*

The number of children who die is small compared to that of adults. However, the death of a child has serious and specific repercussions for the family, friends, caregivers, and society. The death of a child seems unnatural.

The broad range and complexity of childhood pathologies (congenital defects, metabolic and genetic disorders, neurodegenerative problems, cancer, cystic fibrosis, etc.) are major challenges for acquiring and maintaining expertise. Some of these conditions are familial and may affect more than one child, which is very hard on a family.

It is often difficult to predict how the illness of a child or adolescent will progress, which leads to greater uncertainty in prognoses. This is due to the rarity of certain illnesses and the arrival of new technological advances.

The duration of the palliative phase varies much more among children and adolescents than adults, and can even span a number of years.

The healthcare objectives for children with life-threatening conditions are not limited to a choice between curative and palliative treatment. Children who in the past would have died quickly can now live longer thanks to sophisticated new techniques: assisted breathing, organ transplants, genetic manipulation, intra-uterine surgery, artificial hearts, parental nutrition, and new pharmacological treatments (notably to treat cancer, cystic fibrosis, and heart disease). However, these advances have made healthcare more complex and increased the burden for families.

Even more so than with adult patients, the family unit is the central concern of the entire caregiving team.

Children are still in the process of maturing physically, emotionally, cognitively, socially, and spiritually, and this can be seen in how they express themselves and understand illness and death. This continuing physiological development can also influence the clinical expression of symptoms and pharmacokinetics. Caregivers must be aware of a child's phase of development and adapt their care appropriately.



Children and adolescents have a primordial need to continue routine activities (including school and play time) according to their physical capabilities and stage of development. This need is sometimes overlooked and underestimated among children and adolescents with an uncertain future.

Obtaining consent poses its own challenges for children and adolescents. From an ethical standpoint, we should always seek the consent of the child or adolescent, even if this is not always compulsory. Studies conducted in this field in Great Britain<sup>29</sup> identify four levels of child participation in the decision-making process: being informed, being consulted, having views taken into account in decision making, and being respected as the main decision maker.

With regard to confidentiality, the choice of treatments, and “DNR” orders, certain legal issues have particular bearing on minors. Minors aged 14 or more may give their own consent for the care their condition requires; in addition, they and those holding parental authority have the right to access their health record. However, two issues require further clarification: the notion of child consent and clarification of the laws (*Civil Code* and the *Act respecting health services and social services*).

#### *Categories of children needing palliative care*

There are six categories of children needing palliative care. The first four groups were defined in 1997 by the Association for Children with Life-Threatening or Terminal Conditions and their Families and the Royal College of Pædiatrics and Child Health. The fifth group was defined by The Lighthouse, Children and Families.<sup>30</sup> A sixth group was added following discussions by the Working Group On Pediatric Palliative Care.

#### **Group 1:**

Children presenting conditions for which curative treatment is possible. Palliative care treatment may be necessary during periods of uncertainty or when treatments fail to cure the affected child. Examples: Cancer and major cardiac, renal, or hepatic involvement

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<sup>29</sup> Royal College of Pædiatrics and Child Health, “Withholding or Withdrawing Life Saving Treatment in Children.” London: 1997.

<sup>30</sup> The Lighthouse, Children and Families, “The Concept of Respite for Families of Children with a Life-threatening Illness. Evaluation and Perspectives for Improvement November 2000.”

**Group 2:**

Children with conditions that require long periods of intensive treatment to prolong their life and enable them to participate in normal activities for children their age. Examples: Cystic fibrosis, muscular dystrophy

**Group 3:**

Children with progressive conditions offering no hope of recovery, where treatment is solely of a palliative nature and may last for years. Examples: Batten disease, mucopolysaccharidosis

**Group 4:**

Children with conditions involving severe neurological problems leading to vulnerability and increased susceptibility to complications, and that may lead to deterioration that is unpredictable but not considered progressive. Examples: Accidents with neurological damage, severe cerebral palsy

**Group 5:**

Newborns with a very limited life expectancy. A protocol on caring for these children was published<sup>31</sup> recently.

**Group 6:**

Children who suffer trauma (intentional or not), sudden infant death syndrome, or stillbirth. The care and services are intended for the child's family and loved ones.

*Moving from a curative approach to a palliative one*

The distinction between curative and palliative objectives in healthcare is becoming increasingly unclear. The services required to meet the needs of children and their families should not force parents to choose between the two. Curative and palliative care can be combined to better meet the patient's needs, avoid the need for crisis management, be proactive in care and decision making, and focus on the patient's quality of life. By integrating the two, we avoid service fragmentation, improve coordination, and reduce treatment delays for children and their families.

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<sup>31</sup> Catlin, A. "State of the Art, Creation of a Neonatal End-of-Life Palliative Care Protocol." *Journal of Perinatology*, no. 22 (2002): 184–195.

In pediatric palliative care, curative and palliative care must be combined to pursue a number of objectives simultaneously. The focus on each individual approach may vary according to the circumstances.

The U.S. Institute of Medicine stresses that integrating palliative care immediately after diagnosis of a life-threatening illness improves the care the children receive whether or not they survive and helps the families of these children.<sup>32</sup>

### *Organization of services*

Children and adolescents die from a variety of causes and at a range of different ages. They may fall seriously ill and suffer complex problems or be victims of an accident. They may die at home or at a healthcare facility, in the pediatric or neonatal ward, in pediatric intensive care, in the emergency room, or, when healthcare services are adapted to the child's needs, in a respite care home or hospice. Services must therefore be organized in such a way as to meet their specific needs no matter where services are being provided.

When a child and his or her family return to their area of residence, local resources must play an important role in the child's care. As such, it is crucial that the caregiving team from the hospital support local caregivers and transfer all necessary information to them. Currently, it is important to ensure services are well coordinated and that there is effective communication between the various service providers (CLSC, family doctor, pediatrician, hospital staff, pharmacies, community organizations, etc.), to ensure the child and his or her family receive the right services at the right time, based on their needs and choices.

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32 Institute of Medicine, "When Children Die: Improving Palliative and End-of-life Care for Children and Their Families." Washington: National Academy Press, 2002.

## **8. Responsibility Sharing, Resource Allocation, and Accountability**



## **8. Responsibility Sharing, Resource Allocation, and Accountability**

This policy covers numerous clinical and organizational issues. It identifies deficiencies and suggests a model to better adapt and improve end-of-life services. For the policy's objectives to be met, resources will need to be allocated consistently for the various levels of responsibility, and a system of accountability will have to be implemented with regard to the results obtained.

Planning, resource allocation, and accountability efforts must focus on the following objectives:

- Regional planning for all services to organize a consistent way to meet the needs of all palliative care patients and their loved ones that is mindful of their wishes
- Improved resource distribution between regions and between types of care (curative versus palliative), notably to correct the discrepancies in access to palliative care services
- Accountability based on achieving targets set out in management agreements, with the choice of means left to the local service network development agencies and service providers according to their respective levels of responsibility

### **8.1 MSSS**

Generally, MSSS adopts general orientations, sets national objectives, and allocates resources to the local service network development agency.

The Palliative Care Policy is a sectoral policy that complements and supports other orientations defined in relation to client programs. In certain cases, it builds upon policy documents such as the Home Support Policy, Québec Cancer Control Program, and Orientations for the Frail Elderly.

MSSS sets provincial palliative care objectives for the client program in question (physical health). These objectives are included in management agreements between MSSS and the development agencies.

The method for allocating resources to local service network development agencies is currently under review. It will make it possible to

- Allocate an overall regional budget for all services based on the social and health characteristics of the population

- Help make continuous improvements to performance
- Promote more effective and efficient solutions

MSSS will also have the following major responsibilities with regard to the policy:

- Distributing the policy
- Promoting its implementation throughout Québec
- Promoting excellence and research
- Monitoring and assessing the policy, and implementing the mechanisms needed to have access to important information, notably in information systems

## **8.2 Local Service Network Development Agencies**

As per MSSS policy, local service network development agencies are responsible for the development of local service networks, service planning, and resource distribution in their regions.

Generally, agencies must...

- Distribute and explain the policy to local bodies
- Develop regional action plans that take MSSS objectives into account
- Organize services in the region in accordance with these objectives
- Allocate resources to service providers based on regional preferences, and ensure accountability
- Report back to MSSS on the basis of indicators identified by MSSS in management agreements
- Produce an annual report on progress toward policy implementation

Regional targets by client program determine the local organization of services. Resources are allocated to the various service providers by the local service network development agencies based on regional preferences. Accountability is to measure results.

The measures to be implemented under this policy are discussed in detail in chapters 5 and 6 of this document. The responsibilities of the various bodies are explained where necessary.

### **8.3 Service Providers**

Service providers are responsible for organizing and delivering services to users and families in their regions. Provided they respect MSSS objectives, they may choose which means to use to meet the Regional Action Plan service organization objectives, based on the resources allotted them. Service providers must work together as partners to ensure a continuity of services.

More specifically, service providers are responsible for the following:

- Implementing the measures set out in the Regional Action Plan according to MSSS objectives
- Delivering the services that users and families need
- Ensuring accountability at the regional level





## **9. Monitoring and Evaluation Framework**



## **9. Monitoring and Evaluation Framework**

### **9.1 Evaluation Context**

In accordance with the new *Public Administration Act*,<sup>33</sup> the Palliative Care Policy (PCP) must be evaluated, just like any other department program, policy, or strategy. This evaluation allows us to measure the appropriateness of the PCP, assess the degree to which actions taken and results obtained match those initially planned, identify the degree to which objectives have been met, and, as the case may be, suggest ways to more effectively meet these objectives.

### **9.2 The Purpose and Objectives of Monitoring and Evaluation**

The monitoring and evaluation framework provides a comprehensive look at what needs to be assessed, and allows us to target those aspects that will need to be adjusted as the PCP is introduced and implemented. The monitoring and evaluation framework is meant to act as a platform to support a rigorous information gathering and analysis process with a view to evaluating the policy and periodically facilitating the decision-making process for all concerned.

The goal of the monitoring and evaluation framework is to ease the policy introduction and implementation process. More specifically, evaluation objectives include

- Assessing the degree to which the proposed measures have been implemented with regard to the basic objectives
- Measuring the results obtained once the policy is introduced and implemented

There are three key aspects to the monitoring and evaluation framework:

- 1st Aspect: Monitoring the introduction and implementation of the measures
- 2nd Aspect: Continuously evaluating expected results
- 3rd Aspect: Evaluating certain precise objectives on an ad hoc basis

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<sup>33</sup> Secrétariat du Conseil du trésor. “L’évaluation de programme, document destiné aux dirigeants et dirigeantes de ministères et d’organismes.” Québec City: Sous-secrétariat aux politiques budgétaires et aux programmes, 2002; p. 22.

### 9.3 Main Prerequisites for the Monitoring and Evaluation Framework

One prerequisite is that there be sufficient access to reliable, valid information to ensure the quality of the evaluation.<sup>34</sup> In some respects, this represents a challenge. In Québec, some provincial databases or information systems have been designed so that use of services can be measured. However, certain factors—including data coding—prevent the data from being used to its full potential. Moreover, to compile information on the path of user services through the various care environments,<sup>35</sup> hospital data must be presented in relation to data on the use of ambulatory and home healthcare services for patients receiving palliative care.

Among other prerequisites, a formal monitoring and evaluation mechanism must be initiated early in the PCP planning or implementation process. This committee is key to the success of this framework. It will also serve to ensure the evaluation is able to meet its own objectives. This will allow the evaluation to provide the necessary feedback to optimize the fulfillment of policy objectives.<sup>36</sup>

Generally, this committee will be responsible for ensuring that human, material, and financial resources are available to conduct this evaluation; specifying the context, challenges, issues, and monitoring activities related thereto; determining the indicators and making sure they are tracked; planning the completion schedule; and stipulating evaluation result feedback mechanisms.<sup>37</sup>

### 9.4 General Evaluation Schedule

Evaluation efforts under the monitoring and evaluation framework should be initiated six to eight months after the policy's official launch date.

Due to the specific nature of the first aspect, *Monitoring the introduction and implementation of the measures*, and the second aspect, *Continuously evaluating expected results*, the evaluation activities planned for these two strategies may start at the same time.

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<sup>34</sup> *Idem*, p. 16.

<sup>35</sup> Gaudette, L.A. "Developing Palliative Care Surveillance in Canada: Results of a Pilot Study." *Journal of Palliative Care* (2002): 18 (4); p. 262–269.

<sup>36</sup> Ministère de la Santé et des Services Sociaux (Desrosiers H., Kishchuk N., Ouellet F., Desjardins N., Bourgault C. and Perreault N.). *Cadre de pratique pour l'évaluation de programmes. Applications en promotion de la santé et en toxicomanie*. Québec City: 1998; p. 130.

<sup>37</sup> Comité Consultatif sur le Cancer. *Op. cit.*

## **Conclusion**



## **Conclusion**

Palliative care will undergo significant growth in the coming decades. Certain demographic and sociological trends in Québec society will inevitably lead to expansion. The health and social services system will come under considerable strain to as it seeks to meet the complex needs of an increasingly numerous and demanding clientele.

We must re-examine how end-of-life services are delivered so that the health and social services system can provide patients and their families with quality services in a timely fashion. Considerable effort will have to be expended to meet growing demand. Healthcare workers must be better equipped to recognize when palliative care is required. True dialogue must be introduced between patients, their families, and healthcare workers on the one hand, and among healthcare professionals themselves on the other. In the palliative stage, the focus must be on responding to the psychological, spiritual, and social needs of patients and their loved ones, in addition to relieving their symptoms and physical pain. Interdisciplinary teamwork will be paramount at every level so that the interests of patients come first and the complexity of end-of-life needs are taken into consideration.

End-of-life service organization modes will have to be re-examined to better meet the growing demand for palliative care. Keeping patients in their natural living environments as long as possible—if feasible and if so desired by patients—will dictate how services are organized. This does not take anything away from other care facilities that have an important role to play when situations require them or patients choose them.

Service providers must also be given the resources they need in order to attain the desired results. For our society to be able to meet the ever-growing demand, community organizations will have to work together with the private sector. The government must see to it that Québec's legal framework and standards of quality are upheld.

This policy offers a main set of guidelines on how end-of-life services should be structured for all patients. In addition to explaining the context and main challenges facing Québec society, it offers concrete solutions and measures to foster accessibility, continuity, and quality of services. Lastly, it places patients' needs and wishes at the heart of the planning and service delivery process.

More thought must be given to certain types of clienteles, such as those lacking in capacity, including those represented by the Public Curator. For such people, the notion of free and informed consent presents some obvious difficulties. Managing symptoms, pain, and anxiety can be a real challenge for caregivers when the patients' condition makes communication difficult.





**Typical Case History of an End-of-Life Cancer Patient,  
Under the Palliative Care Policy**



## Typical case history of an end-of-life cancer patient under the palliative care policy

### Clinical history

-1-

Mr. F.X. Voyer, 67, is diagnosed with stomach cancer after being referred by his family doctor to a hospital gastroenterologist. After surgery, he is treated with chemotherapy and radiotherapy by the hospital's interdisciplinary oncology team and monitored as an outpatient. The illness goes into remission and Mr. Voyer continues to live at home during this period.

-2-

Two years later, Mr. Voyer's condition worsens. He is hospitalized for a few days. A relapse of the cancer is observed with distant metastasis. The interdisciplinary oncology team discusses the possible options and decides to forgo other treatment. Mr. Voyer and his family are kept up-to-date and take part in the entire decision-making process. The hospital palliative care team works closely with them and offers its expertise, notably with regard to symptom and pain management and to support the caregiving team in the difficult transition from curative to palliative treatment. After consulting with colleagues and examining the available data, the attending

### "Administrative" history

-1-

Upon diagnosis, the service provider gives Mr. Voyer the appropriate support and, with his consent, puts him into contact with his local CLSC. He also gives Mr. Voyer an information leaflet on the steps to take. The service provider (hospital, outpatient clinic, emergency room, medical clinic, etc.) recommending this approach gives the patient the necessary contact information and directs him to the appropriate resources. The primary healthcare worker on the oncology team forwards all necessary information to the CLSC to ensure a mutual understanding of the situation.

Referring Mr. Voyer to the CLSC at this stage may help to give him the assistance he needs to preserve or regain his sense of worth. In addition, the possibility of establishing relationships with community resources at this point will promote better care in his living environment down the line if the illness worsens and palliative care becomes a necessity.

-2-

At an appropriate time after curative therapy ceases to be an option, Mr. Voyer is informed about the palliative approach and the possibilities available to him and his family. The primary caregiver from the oncology team (or liaison agent) brings Mr. Voyer's situation to the attention of the community palliative care coordinator (hereafter "service coordinator") who works at the CLSC.<sup>38</sup> Mr. Voyer is contacted in the next 24 hours and scheduled to meet no more than a week later with a CLSC professional for a more in-depth evaluation of his needs. The oncology team has already forwarded the necessary information to the CLSC. A discussion is held between the CLSC and the primary oncology caregiver from the hospital.

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<sup>38</sup> The patient or his family may also contact the CLSC on their own.

physician estimates that the patient has six months to live. Mr. Voyer then returns home after spending a few days in the hospital. He receives personalized care at all times.

-3-

After speaking with the service coordinator who has the results of the evaluation results in hand and is very familiar with the community resources available, Mr. Voyer opts for in-home palliative care for an indefinite time. His family also takes part in the discussion and decision making. Mr. Voyer's desire not to be resuscitated in the event of an emergency is understood by all.

His home (bed, chair, bathroom, etc.) is adapted for the delivery of services. A staff of qualified palliative caregivers working in an interdisciplinary team give him the appropriate care for his physical, psychological, and spiritual needs. His family also receives psychological support.

A community organization provides Mr. Voyer and his family with assistance for certain services: shopping, meals on wheels, etc.

Once a week, Mr. Voyer also goes to the hospice day center in his region, for therapeutic baths among other things. His visits to the day center also allow him to reduce his social isolation. He appreciates the contact with the volunteers and other people suffering from serious illnesses.

The service coordinator<sup>39</sup> organizes the services Mr. Voyer receives based on his needs, personal wishes, and the missions of the various service providers in the region. Close cooperation between professionals and solid coordination mechanisms ensure that services are delivered seamlessly between the hospital and at-home care.

-3-

The service coordinator makes sure that the CLSC takes care of Mr. Voyer. An intervention plan is established following the evaluation conducted earlier in the process. Mr. Voyer's wishes are recorded in his file. A primary caregiver from the CLSC will be selected. Various CLSC programs come into play, including ambulatory services, a hotline, and the interdisciplinary palliative care team that supports professionals in the home care program.

The service coordinator also makes sure that medical services are available 24 hours a day, 7 days a week. He or she draws on the medical care network made up of doctors from family medicine groups (FMG), medical clinics, and CLSCs. The service coordinator also makes sure the patient receives round-the-clock pharmaceutical services by calling on community pharmacies, and, if necessary (e.g., at night), hospital pharmacies. For the weekend, preprepared doses of medicine are available at the CLSC, which has drawn up a narcotic management policy. The doctor and pharmacist are part of the interdisciplinary team.

The service coordinator gets in touch with a non-profit organization that provides community support. He or she also makes arrangements to find a spot for Mr. Voyer at the hospice day center in his region, and sets up transportation (through the same community organization that handles his shopping) to and from the day center twice a week.

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<sup>39</sup> These people are also called "case managers." Although from an administrative perspective they work for the CLSC, they act as a shared resource for the various service providers. They too are part of the interdisciplinary teams.

-4-

After three months of home care, the patient's family is exhausted and needs a break. Mr. Voyer's wife, who is now retired, needs time to rest, and the children have had to take a number of days off work to care for their father. They therefore decide to take a break and have Mr. Voyer cared for in temporary accommodations away from home. Based on his own wishes, and since a bed was available, Mr. Voyer spends two weeks at a long-term care facility (CHSLD) where he occupies a bed assigned to palliative care.

-5-

After his temporary stay at the CHSLD, Mr. Voyer and his family express the desire for him to return home and receive his care there. This second stint of home care lasts one month. As Mr. Voyer's health is rapidly deteriorating, the intensity of services increases.

Mr. Voyer's son decides to take leave from work to care for his father, and is eligible for tax measures that partially compensate him for the loss of income. This leave has no effect on his employment status or employee benefits.

-6-

Mr. Voyer's health continues to deteriorate. He has no more than about six weeks to live. After speaking with the service coordinator, Mr. Voyer and his family agree that remaining at home has become too great a burden. A variety of solutions are possible: Mr. Voyer could be transferred back to the hospital where he had received curative treatment, or to a regional hospital equipped with a palliative care unit. They ultimately opt for a hospice specialized in palliative care seeing as Mr. Voyer's condition qualifies him for admission. They feel that they will be more at ease at such a facility.

-4-

The service coordinator takes part in the discussion. He is responsible for quickly finding temporary accommodations at the CHSLD, which has two beds open. The patient receives appropriate care for his condition administered by qualified palliative care personnel. The CLSC is responsible for communicating with the CHSLD concerned and transferring all necessary information. If needed, the CLSC's resources (e.g., social worker) are on hand to ensure better coordination.

Temporary accommodations could have just as easily been located at another healthcare facility (hospital, specialized hospice, etc.).

-5-

The service coordinator reinitiates Mr. Voyer's home care services. The doctor and pharmacist are available at all times to adjust his medication. They offer their support to the nurse. She consults with them to plan how often Mr. Voyer will need home visits. The service coordinator takes the necessary steps with the pharmacy to get a pump to administer morphine to the patient.

At this stage, Mr. Voyer might have been hospitalized for a few days in a palliative care unit if his pain had not been sufficiently relieved.

-6-

The service coordinator finds a spot for Mr. Voyer at the hospice, which has ten beds available in palliative care and admits patients regardless of their age or type of illness. The patient's life expectancy is not an absolute criterion of admission.

Based on Mr. Voyer's clinical condition, he feels that a transfer to a hospice is a good idea as it is equipped to satisfy his needs as well as those of his family.

The CLSC arranges his transfer and makes sure the hospice has all the necessary information. It also notifies the primary caregiver on the interdisciplinary oncology team that treated Mr. Voyer.

Mr. Voyer is admitted to the hospice in his region. He stays there for five weeks. On a number of occasions, the supraregional palliative care team provides the hospice staff with telephone support. An experienced team from a regional hospital or CLSC could also have provided this support.

Mr. Voyer dies surrounded by loved ones, after receiving all the appropriate treatment to ease his symptoms and pain. Death is quickly pronounced on site by the on-call physician. The body is collected by a funeral home after the family has had the time to say goodbye to the deceased. The deceased's family had access to support throughout Mr. Voyer's stay at the hospice; and, if desired, a psychologist or social worker will meet with them after the death to help them deal with their grief.

The hospice is staffed by experienced personnel who offer all the services Mr. Voyer's condition requires. The hospice draws on its partnerships with other service providers in the region (CLSCs, hospitals, FMGs, medical clinics, pharmacies, etc.) with which it has formal agreements or service contracts. As such, the hospice can notably draw on the support of the interdisciplinary palliative care team at the CLSC or hospital, or supraregional team for extremely complex cases.

After the patient's death, the hospice makes sure that death is quickly pronounced by a physician. A few hours later, the service coordinator receives information regarding the death. The hospice and the deceased's family make provisions for the body to be collected by a funeral home.

The hospice helps the deceased's loved ones with their expected bereavement and refers them to resources in the community for help dealing with normal and pathological grief.

The service coordinator makes sure the deceased's family is helped by community resources in dealing with its grief.

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