



A Provincial Framework for End-of-Life Care



Ministry of Health | May 2006

Letter from the Minister

British Columbia continues to develop a health care system that encourages choice and dignity, along with quality and patient-centred care, for people nearing the end of their life.

Our Provincial Framework for End-of-Life Care gives health authorities, service providers and community groups a basis for planning exemplary end-of-life care services.

The framework builds on the solid foundation of care services developed by dedicated family members, volunteers, health care professionals and service providers over many years. It follows on the substantial work of provincial and national planners to advance care and support for people in the final stages of their life.

In presenting this framework, the province acknowledges the many British Columbians who contributed to the discussion paper on a provincial end-of-life care strategy that informed the final document. As well, we would like to take this opportunity to thank the many volunteers who give of their own time to ensure families experiencing serious illness have compassionate support during this difficult time.

Thank you again for your efforts in assisting us to create a health care system that aims to ensure quality care at the end of life.

A handwritten signature in black ink that reads "George Abbott". The signature is written in a cursive style with a large, stylized initial "G".

Honourable George Abbott
Minister of Health

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Introduction

The way we care for and support people who are dying, and their families, is one of the measures of our society and the social programs we provide.

The Government of British Columbia is committed to establishing high quality end-of-life care and support as an integral part of our provincial health system. The publication of the Provincial Framework for End-of Life Care reflects this commitment. The province will work with health authorities, service providers and community groups to build on our existing services to create a system of exemplary end-of-life care.

The medical developments of the last century or so have yielded dramatic improvements in our overall quality of life, but they have been accompanied by an increasing medicalization of the dying process. Compared to earlier times, most of us have little direct experience of death. British Columbians are consequently unfamiliar, and sometimes uncomfortable, with what is the inevitable, final part of life.

These medical developments, along with other societal changes, have also led to significant shifts in the most prevalent causes of death and in the typical process of dying.

More than 90 per cent of deaths today occur as the result of end-stage and/or chronic health conditions, such as cardiovascular or respiratory disease or cancer. Although most of these deaths are, therefore, expected, it is still the case that around 60 per cent of British Columbians die in hospital. This happens even though

we know that a large majority of the population would prefer to spend their final days at home, in familiar surroundings, with their families and friends around them. We also know that many of the people who currently die in hospital could, with appropriate preparation and support, die at home. This includes people whose home, in their final months or years, is a residential care facility. There are others who, for various reasons, cannot or do not wish to die in their own home. These people could die in the more peaceful surroundings of a hospice, rather than in an acute care hospital.

End-of-life care is continually evolving and, as British Columbia's population grows and ages, government recognizes this area is an expanding priority. Great improvements have occurred over the last two or three decades in palliative care and, particularly, in our ability to manage pain and other unpleasant symptoms. By combining the best of modern clinical palliative care with services to support people's social, psychological and spiritual needs, society has the means to deliver a very high standard of end-of-life care. Our challenge now is to take the steps necessary to ensure quality services are consistently available, so that British Columbians with a life-limiting illness, and their families, can experience the best possible quality of life during the transition to death.

Looking at the wider health system, it is clear that the time is right to enhance end-of-life care. Governments are identifying and making the critical changes necessary to ensure the publicly funded health system remains sustainable in the face of various anticipated future

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pressures, including the aging of British Columbia's population. Quality end-of-life care, delivered as part of the mainstream health system, is consistent with a number of actions considered crucial to effective health system redesign:

- Today's acute care hospitals provide increasingly sophisticated and expensive services. Not everyone needs this intensive level of care and many could be cared for in other settings. This would help to ensure hospital services are available, in a timely manner, to people who need them.
- Home care is one of the most effective ways of meeting health care needs that do not require hospital treatment. It is also one of the best ways of increasing the number of people who can die in their own homes. Home care delays hospital admission until it is absolutely necessary.
- Effective primary care and chronic disease management services are widely regarded as necessary for the health system. With appropriate backup, primary care providers (family physicians and other health professionals familiar with the patient) could play a greater role in end-of-life care.
- In all parts of the health system, the aim is to provide high quality services that meet the patient's needs and preferences. End-of-life care is a prime example of a service area that needs to be patient-centred.

Although improvements in end-of-life care are ongoing, we are fortunate in British Columbia to have a solid foundation on which to build. There are many individuals working in the health and

social services system who are well versed in the means of providing high quality end-of-life care. These individuals can be found in numerous settings, including health authorities, palliative care units, palliative response teams, home care programs, hospice societies, in private practice and in the academic and research communities.

Many of these same people have already been involved in previous provincial and national initiatives to advance palliative and end-of-life care. They include the lengthy national consultation process that led to the 2002 publication, *A Model to Guide Hospice Palliative Care*, by the Canadian Hospice Palliative Care Association. Many also contributed and responded to the province's 2002 Discussion Paper on a Provincial Strategy for End-of-Life Care in British Columbia.

As a government, and as a collection of groups and individuals with common aims, British Columbia is in a good position to accept the challenge to build an end-of-life care system that will provide a high standard of care so that, whenever possible, British Columbians can finish their lives in the manner and location of their choosing.

Definitions

End-of-Life Care

"End-of-life care" is the term used for the range of clinical and support services appropriate for dying people and their families. The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying people and their families.

Palliative Care

“Palliative care” means the specialized care of people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term “palliative care” is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure.

Hospice Palliative Care

“Hospice palliative care” is a philosophy of care that stresses the relief of suffering and improvement of the quality of living and dying. It helps patients and families to:

- address physical, psychological, social, spiritual and practical issues and their associated expectations, needs, hopes and fears;
- prepare for and manage self-determined life closure and the dying process; and
- cope with loss and grief during illness and bereavement.

Notes on Terminology

Many different definitions can be found for the above terms. Those provided here are taken from a variety of representative, recent sources.

Dame Cicely Saunders of the United Kingdom is credited with conceiving the modern “hospice” movement in the 1960s as an approach to providing holistic care for the dying.

“Palliative care” was coined by Dr. Balfour Mount in 1975 as a term acceptable in both English and French.

“Palliative care” has generally been used in hospitals and other large institutions.

“Hospice care” is more often associated with community programs that have usually developed as separate, voluntary organizations.

“Hospice palliative care” is a term that has been adopted by many organizations, including the Canadian Hospice Palliative Care Association, to encompass both sets of programs and origins. It unifies the overall movement and establishes common sets of principles and objectives.

“End-of-life care” is a more recent and more literal term that has been used, for example, by a subcommittee of the Government of Canada standing senate committee on social affairs, science and technology that has studied this issue. This term has generally been adopted to make it clear that a person dying from any cause, other than a completely sudden and unexpected one, might benefit from the services typically provided through palliative/hospice care. The terms “palliative” and “hospice care,” in practice, have often been associated with a limited number of diseases, primarily cancer. Hence, the use of “end-of-life care” means an intention to offer specialized, holistic services to the wider group of people approaching death.

In many instances, these terms are used interchangeably. For the main part, “end-of-life care” will be used in this document with the above meaning.

Although the term “hospice” is sometimes used to mean a general approach to care or a set of supportive services (similar to “hospice palliative care”), it is also used as a noun to refer to a building in which people spend the last days or

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Health care providers, health authorities, community groups and voluntary organizations will work closely together to create and deliver an effective system of end-of-life services that are well planned and well co-ordinated.



weeks of their lives. In this document, where “hospice” is used as a noun it refers to such a specialized facility and the services provided within it. Community groups providing supportive services such as information, counselling and bereavement support are often known as hospice societies. Most of them, however, do not operate residential hospices.

Finally, where the term “family” is used in this document it should be taken to include both formal family members of the dying person and other individuals with close personal connections to the dying person.

Vision

End-of-life care in British Columbia will be an essential part of the health service system. It will feature high quality services that are competent, compassionate and respectful of all people who are dying and their families. Patients and families will have choices, including a range of options to support death with dignity and comfort in the setting that best meets the needs of patients and family caregivers. Health care providers, health authorities, community groups and voluntary organizations will work closely together to create and deliver an effective system of end-of-life services that are well planned and well co-ordinated.

Principles

Access to appropriate, high quality services and support should be available to any British Columbian who needs end-of-life care.

The following, more specific principles guide all aspects of end-of-life care:

- 1. Patient and Family Centred** – Care and services should be planned and delivered based on consideration of the patient and family as a unit with individual and collective needs and wishes. Providers should be sensitive to the particular personal, cultural and spiritual values and beliefs of the patient and family. The individual’s and family’s preferences should be solicited and respected in care delivery.
- 2. Ethical** – Care providers should respect the autonomy of the individual, their right to confidentiality and privacy and the ethical principles common to their culture. They should be straightforward and honest with the person and family and behave in accordance with all applicable standards of professional practice.
- 3. Enhancing Quality of Life and End of Life** – The primary objective is to enhance the quality of the individual’s remaining life and to ensure they and their family experience as satisfying an end to life as is possible. In particular, care and support should be based on the assumptions that:

- they affirm life and treat death as normal;
 - they generally neither hasten nor postpone death;
 - the person should be helped to live as actively as possible for as long as possible;
 - the individual should be free from avoidable distress and suffering; and
 - the family should be actively supported in their bereavement, as well as during the dying process.
- 4. Accessible** - Appropriate services should be available where people live or, if this is not feasible, as close as possible to where they live, in the setting that is preferred by the person and their family and in a timely manner. Regardless of their particular disease, end-of-life services should be available to all people who want them, including children and younger adults.
- 5. Effective** - To be effective, services and supports should be:
- evidence-based and consistent with appropriate sets of standards, norms and practice guidelines;
 - holistic, integrating services that respond to all of an individual's and family's physical, psychological, social, emotional and spiritual needs;
 - delivered by competent, well-trained providers, including volunteers, with the appropriate knowledge and skills and with the necessary expert back-up; and
 - well co-ordinated, using effective communication systems.

6. Collaborative – Services should be developed and delivered collaboratively.

- At the individual level, service providers of all types who are involved in a patient's and family's care need to communicate and work with one another, and with the recipients of care, to ensure services run smoothly and issues are responded to effectively as they arise.
 - At the system level, health authorities, service providers and other organizations (including community groups) need to work closely together to develop a workable system of services that makes the most effective use of the skills and resources of the various individuals and groups.
- 7. Adequately Resourced and Cost Effectively Delivered** - It is important to devote adequate and appropriate resources to end-of-life care. As governments invariably face competing pressures for limited funds, it is also important to ensure that end-of-life services are delivered in the most cost-effective, affordable way possible.

End-of-life services should be available to all people who want them, including children and younger adults.



Key Services

Introduction

This section sets out the key services and other elements that need to be present in a well-functioning system of end-of-life care. It identifies the key services and where (in what settings) they need to be available. The descriptions of the services are organized by the service location (home, residential facility, hospice and

There is a recurring process that all care team members, as well as planners and managers, are advised to consider.



hospital), but it should be noted that many of the services need to be available across all settings. There is also some guidance on how the various services can best be delivered (for example, the characteristics that are likely to make the services as effective as possible).

This framework is not intended to be prescriptive in terms of exactly how services should be organized or delivered in any particular location. It is appropriate that health authorities and other local groups have the flexibility to determine how end-of-life care can best be delivered. This allows health authorities to plan for the particular characteristics of the communities and services for which they are responsible, provided the services are consistent with the overall principles and objectives outlined in this document.

Finally, although overall targets for the shift to fewer deaths in hospital are being established, it is also reasonable that the rate at which those shifts can occur will vary from place to place. The pace at which increasing proportions of patients can be supported in community settings will need to be monitored and reassessed over time. This will occur as the networks of end-of-life services develop and as the public becomes more accustomed to the services and options available to them. It will be important to ensure that, in all parts of the province, end-of-life services for all who can benefit from them are being attended to, developed and improved, in line with the overall directions established in this framework.

Cycle of Care

End-of-life care begins whenever it becomes clear that a person has a deteriorating illness that will lead to death. It continues until the family members have been supported in their bereavement. Throughout the many therapeutic encounters that occur, there is a recurring process that all care team members, as well as planners and managers, are advised to consider. This process is set out in the Model to Guide Hospice/Palliative Care produced by the Canadian Hospice Palliative Care Association (2002) and summarized here.

The first stage in the process is **assessment**. This includes continuing assessment by the care team of the individual's and family's various health and other needs, as well as assessment of their capabilities and preferences.

The second stage is **information sharing**. This involves the provision of clear, objective information to the patient and family by the care team and, in turn, the continuing responses of the patient and family to the situations they face and the information they have received.

The third stage is **decision making**. The patient and family are supported to make their own decisions regarding the care and services they do, and do not, wish to receive, both at that time and in the future.

The fourth stage is **care planning** based on the various needs identified and the decisions made regarding care options and preferences.

The fifth stage is **care delivery**, in response to current and anticipated needs and as guided by the care plan.

The final stage is **confirmation**. This stage is a continual checking back to see whether things are proceeding according to the established plans and preferences and that previous assumptions are still appropriate.

The different elements of this cycle will receive more or less emphasis, depending on the nature and timing of the particular service being provided. The overall effectiveness and comprehensiveness of the system of end-of-life care will be improved if all of these stages are kept in mind throughout the design and delivery of end-of-life care.

Home-based Care

Preparation and Advance Care Planning

At a suitable, reasonably early stage, once it is clear that a person's illness is likely to be terminal, a care provider needs to begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way. This will usually occur when the individual is at home or in a residential facility. The first professionals involved at this stage will usually be primary care providers.

The family and individual need to be given, and referred to, information concerning:

- the likely course of their disease;
- the full range of needs they are likely to encounter (psychosocial and practical, as well as health-related);
- the services that will be available if needed; and
- the choices they will be able to make.

Individuals need to be encouraged to consider, in advance, the likely future options for care. They also need to be encouraged to express, by means of advance directives, their preferences for the care they do and do not wish to receive.

At this stage, caregivers need to decide on the likely members of the care team that will be required, the roles that the patient and family members will play and the means of communication and co-ordination of services. The team should include all of the formal caregivers (including community groups and volunteers) and informal caregivers (family and friends) who will be available to help.

Pain and Symptom Management

The management of pain and other distressing symptoms is one of the primary concerns in end-of-life care. Care to keep the patient in comfort will usually be provided by a combination of physician(s) and home care nurses, with assistance from other formal and informal caregivers, within clearly established parameters and in accordance with clearly documented and communicated plans. For many patients, this type of care may be required around the clock in the days prior to death.

In many cases, the primary care providers will need to consult with specialist clinicians who can advise on any issues that require their level of expertise. On occasion, palliative specialists may need to step in, usually temporarily, to assume direct responsibility for the patient. The nature of this specialized clinical assistance is described further below.

Individuals need to be encouraged to consider, in advance, the likely future options for care.



Out-of-hours support will most likely be provided through specially trained staff reached through a general support line, such as BC NurseLine, or by access to a local, on-call palliative service.



The clinicians with primary responsibility for pain and symptom control, especially where these concerns are more severe, will generally be guided in their practice by established clinical tools such as assessment protocols, clinical practice guidelines and best practices.

Psychosocial, Spiritual and Bereavement Support

As well as dealing with clinical issues, the patient and family have a variety of other needs that must be met. Community groups (such as hospice societies, religious and cultural organizations), in accordance with the various preferences of the patient and family, are often the primary providers of these types of support. It is important that respective roles are clear and that there is regular communication and effective co-ordination. Team members also need to be sensitive and responsive to how the patient and family members are coping.

Support for Informal Caregivers

People who are dying, and especially their families, need assistance with a number of practical issues and activities at a time when they have a great deal to cope with.

Family members will often need a break from these demands. It is important that they are able to get respite services when they need them. Respite should be available in a flexible manner that meets the family members' and patient's needs, both in the family home and in other settings.

Depending on the availability and health of family members, home support is often required to assist the individual and

family with personal care and household needs. In the more intense stages, as death approaches, and as with most team members, home support workers may need to be available around the clock.

Financial Support

Appropriate team members also need to assist the family with various financial and administrative concerns. They include enrollment in the B.C. Palliative Care Benefits Program, which pays for related medications, and with obtaining necessary equipment and supplies.

Specialized Support and Backup

The family, patient and care providers need effective, reliable access to a range of specialized consultation and support services.

Crisis Response – This is one of the most important elements in allowing a significantly higher proportion of people to die at home, rather than in hospital. Crisis response entails the availability of specialist caregivers, around the clock, who can respond as necessary when urgent care concerns arise that are beyond the skills or comfort of the primary and family caregivers.

Specialist Consultation – In a similar manner, primary caregivers need easy access to specialized consultation from palliative experts (not necessarily in a crisis situation) so they can continue to manage the patient's changing needs. This consultation may occur by telephone and other electronic means. On occasion, it may require palliative experts to become directly involved.

Patient and Family Support – Patients and their families, who are registered as part of an end-of-life program, also need to have access by telephone to information and support to help them deal with situations that arise when the primary caregivers (such as home care nurses) are not with them. The process for getting the necessary support may take a variety of forms and may be different in regular, compared to “out-of-hours,” periods. Out-of-hours support will most likely be provided through specially trained staff reached through a general support line, such as BC NurseLine, or by access to a local, on-call palliative service.

Access to Specialized Hospitals and Hospices

Patients whose end-of-life needs can, for the main part, be met at home must be confident that, if they do need the specialized diagnostic and treatment services only available in a hospital, they will have ready access to the appropriate services. They must also have good access to a residential hospice if this is needed, either following a hospital stay or from home. The services provided in these settings are described further below. An important consideration is that the various services are organized and managed in an integrated fashion, so that movement from one setting to another (including returning home if hospital care is no longer needed) is timely.

Residential Care

Approximately a quarter of the people who die each year in British Columbia die in the residential care facility that is their final home. With enhanced support, most

facility residents who now die in hospital could also be supported to spend their remaining time in their residential care facility. With some obvious differences, such as the composition of care teams, most end-of-life services required in residential care facilities are similar to those described for home-based care.

End-of-life care in residential facilities should be planned and managed much as described above, including:

- appropriate advance care planning;
- pain and symptom management;
- psychosocial support;
- specialist support and backup; and
- access to specialized medications and equipment, similar to those available to patients participating in the B.C. Palliative Care Benefits Program.

The regular services available in residential care facilities need to be supplemented, as necessary, to make it possible for quality end-of-life services to be provided to residents who do not need the intensive diagnostic and surgical/medical interventions only available in acute care hospitals.

Hospices

Care in a residential hospice (either freestanding or attached to a hospital, residential care or similar facility) will be appropriate for those :

- who need regular assessment and treatment changes that do not require the full facilities of a hospital;
- where services cannot be provided at home; or
- where the patient does not wish to die at home.

The composition of care teams will vary, according to the organizational characteristics of the hospice and the range of services provided.



The team includes the patient, family members and other informal caregivers and all formal caregivers.



Again, the overall set of services required is similar to those described above. The composition of care teams will vary, according to the organizational characteristics of the hospice and the range of services provided. Nevertheless, hospices should all meet appropriate standards, such as those set by the Canadian Council on Health Services Accreditation. As well, there should be a consistent approach to admission, service provision and client charges.

Hospital-based Services

Even when community services are available, there are patients whose conditions and symptoms require the specialized services of a hospital for some period(s) of time. These periods may or may not include their death. Patients usually require this level of service if they need frequent, specialized, highly skilled assessment and interventions that may include access to diagnostic and treatment services only available in a hospital. The exact nature of the hospital services available will vary depending on the type of hospital and the needs of the patient. They may include care in a specialized palliative care unit or a more general area of the hospital.

These specialized hospital services need to be well co-ordinated. Good communication must be maintained with the members of the community team, including the family, so that the individual's and family's quality of life are maintained. It is also important in case the patient's condition stabilizes sufficiently that they can return home, to a residential care facility or hospice.

System Characteristics and Organization

The previous sections described the services that should be available and the various settings in which they may be provided. This section identifies some of the key elements in terms of how the services are organized and delivered in order to create an effective, seamless, integrated system of end-of-life care. While health authorities, service providers and community groups will retain the flexibility to determine exactly how services can best be organized in their areas, the following elements should be considered and incorporated in their planning.

Co-ordination

As with many other types of care, such as the management of chronic diseases, effective co-ordination of end-of-life services is critical. It is also widely accepted that an interdisciplinary team approach is the preferred way of delivering end-of-life services that are effective and comprehensive.

At the level of an individual case, effective co-ordination is best achieved by ensuring that all members of a care team are identified, share common information about the patient's and family's needs and have clear roles, as well as a means of recording and communicating important information. The team includes the patient, family members and other informal caregivers and all formal caregivers (family physician, specialist physicians, nurses, other professionals and staff and/or volunteers from community organizations). It will generally be helpful to identify a leader for both the formal and the informal caregivers.

At the system level, co-ordination is accomplished by developing recognized networks of practitioners, agencies and disciplines. The form of these networks may vary from place to place. In some cases, formally established interdisciplinary staff teams may provide expertise and support across different settings. In other cases, the networks may be accomplished by making connections among a range of separate individuals and organizations. The important thing is that the various players are connected, have clear roles and good means of communication.

A common system of referral and registration in an end-of-life program will generally be desirable. All professionals should also have access to, and make use of, a common set of educational materials and clinical tools, as well having access to expert backup at all times for consultation and advice.

Support for Professional Caregivers

In addition to receiving expert consultation as necessary, it is important to recognize that professional caregivers who spend a lot of time dealing with dying patients and their families will also have their own needs for psychosocial and other support. These needs should be acknowledged, met and taken into consideration when planning end-of-life care. The needs of formal caregivers who provide services week in and week out will be different from the needs of informal caregivers, who are generally involved throughout the end of life of a family member. Both sets of needs must be recognized and addressed.

Information

The availability and flow of various types of information must be carefully managed in order to deliver good end-of-life care.

At the more general level, members of the public need:

- access to good information on the nature of end-of-life care;
- the issues they or their loved ones are likely to face;
- the choices they will have and the means of expressing those choices, such as through advance directives;
- the types of service and support they can expect to receive;
- various benefits available and any costs involved; and
- how to go about preparing for the end of life and obtaining services.

This kind of information needs to be available in a number of forms. They may include pamphlets, brochures, booklets and similar written materials in various languages and, through the Internet, in electronic form.

At the level of patient information, care teams need to be able to access timely and accurate patient information and to be able to exchange this information efficiently with all staff involved in a person's care, including staff at other settings (such as hospitals). The systems that are set up to accomplish effective management of patient information will vary. Effective co-ordination and good continuity of care will generally suffer if good systems are not in place.

Care teams need to be able to access timely and accurate patient information and to be able to exchange this information efficiently with all staff involved in a person's care.



This framework provides direction and guidance to help ensure that high quality end-of-life care will be available to all British Columbians through the mainstream provincial health system.



Education

Professionals need two broad types of education. First, all health providers who are likely to have some involvement in end-of-life care need improved education on this subject as part of their basic training and as part of their continuing education.

Second, as end-of-life care systems evolve and as the number of people dying increases in the coming years, there will be a need to educate and train more specialized health providers. These include specialist palliative physicians, clinical nurse specialists, nurse practitioners and others. Further in depth training will also be required for generalists, such as family physicians, who take a particular interest in this type of work.

Volunteers, such as those attached to local hospice societies, also need to receive appropriate education to support them in their important role with dying people and their families.

Research and Evaluation

End-of-life services can be enhanced if services and related issues are actively researched and evaluated. British Columbia has a number of university departments with interests, and a wide range of perspectives, in this area, such as medical, nursing, health service delivery, psychological and sociological. Healthy interchange between these groups and those engaged in service delivery will stimulate improvements and innovation in end-of-life services.

Roles and Responsibilities

The overall objective of this framework is to provide direction and guidance to help ensure that high quality end-of-life care will be available to all British Columbians through the mainstream provincial health system. Many different organizations and agencies are involved in end-of-life care. This section lists the general roles and responsibilities of each.

Government

The Government of British Columbia is responsible for providing leadership and setting the overall direction for the health system. This includes setting out policy, making legislative changes (laws and regulations), allocating funds to organizations and individuals who provide services and monitoring their performance, as well as the general progress of the health system.

Publication of this provincial framework provides government's overall direction for end-of-life care. Further direction is being provided to health authorities to identify more specific expectations and requirements.

Government is responsible for legislative changes, within its jurisdiction, that are necessary to improve end-of-life care, such as the regulation of residential hospices.

Government is also responsible for overall funding of the health system, including end-of-life care. As well as funding health authorities to deliver services, government retains direct responsibility for

funding some services that are essential to end-of-life care. These include physician services, ambulance services and PharmaCare.

Finally, in order to monitor end-of-life care, government needs quantitative and qualitative means of determining what changes are occurring and the results of these changes for people who need these services.

Health Authorities

Health authorities are responsible, at the local and regional levels, for organizing and delivering most health services, including most end-of-life care. Some related services (for example, home care nursing, hospital-based services and services in some residential facilities and hospices) are provided directly by health authority staff. Other services are funded, wholly or partly, by the health authority, but delivered by separate organizations or individuals. They include some community-based support services, some residential care and home support services and most hospices. Finally, there are some important end-of-life services that have no formal connection to the health authority. They include care provided by most family physicians and pharmacists, the ambulance service and a wide range of support provided by community groups. These services also need to be incorporated into the health authority's planning and service delivery. Each health authority is responsible for assessing current end-of-life care in their area and planning and implementing changes to improve those services. Health authority staff will generally be in the best position to pull together

the many individuals and organizations involved. They are also best able to establish the connections, relationships and networks of care necessary to make end-of-life services work in an organized, integrated way.

Health authorities must also play the critical role of managing the process of enhancing services to allow a higher proportion of people to die in their homes, including residential care facilities, or in hospice.

Health Professional Groups

Family physicians, and some specialists, are critical members of end-of-life care teams, as are a variety of other professionals. Local, regional and provincial physician and other health professional groups, as well as individual practitioners, will need to work with health authorities, government and others to ensure professional services are organized and delivered in a way that supports high quality end-of-life care.

Other Partners and Groups

Most parts of the province have community organizations devoted to providing assistance to people who are dying and their families. These groups usually depend on community support and fundraising, along with the efforts of volunteers, who are often the major source of psychosocial and bereavement support for dying people and their families. These organizations have an essential role in end-of-life care. Their efforts need to be fully integrated with other end-of-life services. Other groups with an interest and expertise in end-of-life concerns of particular populations

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must also have their needs incorporated into system improvements. Children and youth, and their families, have special end-of-life needs that must be recognised and addressed. Other populations it is important to address include aboriginal people, other ethnic groups, people with HIV/AIDS, street people and those living in poverty.

Accountability

Government is ultimately accountable to the people of British Columbia for the quality of health services in this province, including end-of-life care. The Ministry of Health, in turn, holds health authorities accountable for the delivery of those services they are funded to provide.

This accountability is regularly exercised through the provision of direction (accompanying their budgets), the signing of performance contracts and specified reporting requirements.

As part of health service redesign, the Ministry is requiring health authorities to develop plans consistent with the principles, key services and other contents of this framework that improve end-of-life care. Quantitative indicators reflecting progress in end-of-life service delivery are included in the performance agreements between the Ministry of Health and health authorities, as well as in the Ministry's annual service plan.

The Canadian Council on Health Services Accreditation has developed standards for the delivery of hospice palliative and end-of-life care. These standards, and accompanying reviews, provide another effective means of assessing the progress being made in end-of-life care delivery.

Conclusion

Government is intent on improving end-of-life care so that all British Columbians have access to quality care services. Although many of the services described in this framework already exist in some locations, efforts continue to link these services within an organized, co-ordinated system of care.

Fortunately, there are many people and organizations in British Columbia who are already active and knowledgeable in this field. The task is to bring these groups and individuals together to formalize, expand and co-ordinate their activities.

Improving a complex set of services like end-of-life care calls for a long-term commitment from all involved. This framework is an important component in the commitment to better end-of-life care. The province expects this framework will serve as an important and useful guide to those who can help to build an end-of-life care system that is second to none.

