

Palliative and End-of-Life Care

An introduction to Alberta's framework







Alberta Health Services (AHS) is improving all Albertans' access to skilled health-care providers and the services they need to take better care of people with serious life-limiting illnesses. This plan, which is called the Palliative and End-of-Life Care Framework ensures Albertans have access to the best care possible in their communities amongst their friends, families and loved ones. This document is an introduction to the framework.

What is palliative and end-of-life care?

Palliative and end-of-life care is the set of programs and services that help people who are diagnosed with a progressive life-limiting illness to live their lives the best way possible. These services are not just for people who are actively dying, but also for people with serious progressive illnesses such as lung, kidney and heart disease. People who are aging or living with a serious life-limiting illness who may have many months left to live can benefit from this type of care by having their symptoms and concerns looked after during all phases of their illness. Palliative and end-of-life care is also more than that. It is focused around helping people plan for treatments and options such as where they want to be cared for if they can't be at home. Decisions about health care will be based on a person's choices through Advance Care Planning, which is a very important health policy in Alberta.

Palliative and end-of-life care helps to improve the quality of life for children, as well as adults with a life-limiting or incurable progressive illness and improves care and services that meet their needs. This is done by providing emotional, spiritual and physical support in many different settings (the home, hospitals, nursing homes, hospices and out-patient clinics) during all stages of life.

In addition, palliative and end-of-life care offers help to families and caregivers. Families and caregivers are given information about what to expect in the last months or hours of life.





As partners with health-care providers, they are involved in care planning. Palliative and end-of-life care includes grief and bereavement support groups and workshops for caregivers and families.

In Alberta, hospices are places in the community where people can be cared for in the last months, weeks or days of life.

Your family doctor and health-care providers in your community, such as home care programs, work together to provide care in your

home. Home care providers help many people in the community by meeting the needs of those with progressive life-limiting illnesses and co-ordinating care with physicians who give advice. You can also receive palliative and end-of-life care services through health-care teams across the health-care system such as cancer centres and hospices. Our goal is to increase the skills of all community team members so that people who wish to die at home can do so comfortably.

Why is a palliative and end-of-life care framework needed?

Seniors make up Canada's fastest growing age group. Seniors aged 65 and up will make up 25% of the total population by 2036. As Canadians get older, there will be more people living with chronic diseases and an increase in cancer. Currently, only 16% to 30% of Canadians have access to or receive palliative and end-of-life care services now. Since many Albertans are living with life-limiting serious illnesses, the need for these services will keep growing.

Children who are living with life-limiting and life-threatening illnesses need specialized teams to help them and their families cope with what can be a very difficult time. We need to think about how Albertans are being supported now and what can be done in the near future for families and providers who are caring for a child who is severely ill.

There is now an opportunity to make palliative and end-of-life care services better and more available. The palliative and end-of-life care framework will help to strengthen and improve access to palliative and end-of-life care services for all Albertans wherever and whenever they need it.





How will the palliative and end-of-life care framework benefit Albertans, their families and caregivers?

Adults and children living with a serious life-limiting illness, their families and caregivers will receive the information they need to help them live the best life they can. High quality medical care, comfort and emotional supports will be available during all stages of the illness. Being able to access the right information or the right health-care provider at the right time will help people stay at home longer with better care. The framework's activities will benefit many health-care providers who need the skills and knowledge to deliver care in the best way possible.

How will palliative and end-of-life care be improved for Albertans?

There are five main areas that will help us improve palliative and end-of-life care services for all Albertans. These improvements ensure that we will be able to provide the best programs, services and supports to meet the needs of patients and their families. These resources will be accessible to anyone who needs it, at any age, in any stage of life. These five areas will help us to improve palliative and end-of-life care services.

Program Development

Partnerships and Innovation

Practice and Standards

Education and Awareness

Communication





Program Development

Educating health-care providers is important because it allows them to share information quickly and correctly. When health-care staff members are able to share information about their patients and treat symptoms with well-researched methods, we get better results for Albertans. How all team members in palliative and end-of-life care work together is key to safely meeting Albertans' needs in their community.

Albertans will have

- 24/7 access to information for themselves, their families, caregivers, loved ones and health-care providers
- health-care staff who help patients (with and without cancer) meet their needs
- emergency medical services and trained home care professionals to treat people with life-limiting serious illnesses in their home
- access to more care options, including hospice beds across Alberta
- a website to access information on the palliative and end-of-life care programs and services that are available in the province
- improved volunteer co-ordination and training
- better services and programs for people with life-limiting serious illnesses

Partnerships and Innovation

Alberta has areas of excellent palliative and end-of-life care services and programs that will be spread across the province. We are testing new methods of care and creating programs that will give Albertans more options for care in their communities. We are also learning new ways to work with communities in partnerships that benefit health-care providers and all Albertans.

Albertans will have

- the needs of patients and their families met by improving the strength of communities and providing quality services
- increased support for caregivers and health-care providers





- effective management of symptoms provided to people in all communities
- connections to palliative and end-of-life care services and programs that will improve quality of life
- stronger services and programs, and a higher quality of care for Albertans

Practice and Standards

The framework focuses on standards to make sure health-care providers use the best information and tools available to take care of their patients and their families. Within AHS we can do this by providing resources and guidelines for care, and keeping this information up-to-date and available.

Albertans will have

- resources available to find the information that caregivers need to take better care of patients
- · access to the right providers, programs and services
- policies to support quality patient care
- new programs and services based on research

Education and Awareness

To educate providers and Albertans, information needs to be made available in many ways. Accessible information for training is important to improve knowledge and care.

Albertans will have

- a website for patients and families to access information
- educational programs with up-to-date information for health-care providers and new online resources to find information
- available resources to educate palliative and end-of-life care health-care providers on how to take care of their patients
- consistent guidelines for education and training for health-care providers
- support for palliative and end-of-life care education and awareness in Alberta





Communication

Albertans need to know how their illness can be managed well and be able to find the care and the resources they need. AHS will make this information easier to find and understand. Albertans and health-care providers also need to know what services exist in their community so that they can be improved.

Being able to access information is important. Albertans need a way to tell health-care providers what they need and health-care providers need to share important information with their patients.

Albertans will have

- access to patient information through electronic health records
- improved options for advance care planning to support their choices for health care
- available palliative and end-of-life care information



What will happen next?

In the palliative and end-of-life care framework, we talk about introducing new services and making a plan to improve health-care services for patients, families and caregivers in Alberta.

Many new palliative and end-of-life care programs and services are being put into place in 2014 and 2015. The remaining programs and services, as outlined in the framework, are planned in the coming years. A designated team, which includes patients and families, is working on improving these programs and services.

With health-care providers and communities working together, the framework will be put into action so we can offer better care to Albertans with serious life-limiting illnesses. Albertans have told us about the type of care they need and want when they are facing death. Everything will be done to meet those needs and improve our palliative and end-of-life care services.





We value the teamwork between all levels of health-care providers who need to work together to meet the needs of patients and their families. Relationships will be built to create a system that works so that patients and families will get the care they need and want during all stages of their illness.

Cancer, chronic diseases and other illnesses that affect our life can be managed well with the right care to improve the quality of lives. Alberta has strong communities and educated, skilled "You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

- Dame Cicely Saunders

providers who will make our province a better place for those who are living with advancing, serious life-limiting illnesses. A lot can be done in communities to help people stay home and the palliative and end-of-life care framework is focused around this awareness. Together, we will work on becoming the best we can be and make a plan for the future that supports all Albertans when it matters the most.

Where can I find more information?

Many health-care experts have worked together on the palliative and end-of-life care framework to help change how Albertans are cared for. This plan is available for clinicians, health-care providers and for the public. The following link will take you to the original plan that outlines services and programs, and how we decided that things need to change.

Palliative and End-of-Life Care Framework:

 $\underline{http://www.albertahealthservices.ca/assets/info/seniors/if-sen-provincial-palliative-end-of-\underline{life-care-framework.pdf}}$

Advance care planning is a way to help you think about, talk about and document your wishes for health care. It is a process that can assist you in making health-care decisions now and for the future. For more information, visit Advance Care Planning: www.conversationsmatter.ca





Five areas that will help improve palliative and end-of-life care services for Albertans



Program Development

Emergency medical staff trained with appropriate knowledge

24/7 access to information and support

Advance care planning

Home care offering similar services across the province



Partnerships and Innovation

Government, communities and AHS working together on policies

Establish experts and funding for long-term developments

Specialists helping primary care with managing complex illnesses

Do research that tells us how to measure, how to improve and be consistent



Practice and Standards

Tools and supports for physicians and other providers in communities

Use technology to support providers in remote regions

Research the best ways to provide care

Standards for care across Alberta



Education and Awareness

Increase knowledge of care providers across all health-care sectors

Home care services built around peoples' needs

Helping patients and caregivers find the right information

More teams with the right skills in home care and other care settings



Communication

Better understanding of the benefits of palliative and end-of-life care

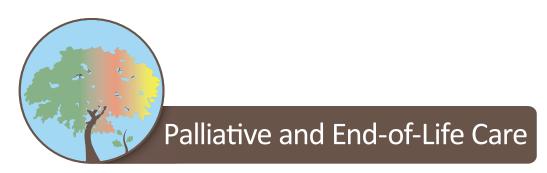
Improved awareness of how to access services

Better planning for future health issues

Timely expert support and safe transitions for patients in health-care locations







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