# Hospice and Palliative Care in Colorado

# 2009 Report to Legislative Council

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### **Committee Charge**

Pursuant to House Joint Resolution 09-1017, the Interim Committee to Study Hospice and Palliative Care is charged with considering barriers and disincentives that prohibit or prevent patients from receiving hospice and palliative care during chronic and life-threatening illnesses. The interim committee was required to meet at least six times during the 2009 interim.

#### **Committee Activities**

The Interim Committee to Study Hospice and Palliative Care met six times during the 2009 interim. The meetings focused on a variety of topics including an overview of hospice and palliative care, barriers to accessing and utilizing hospice and palliative care, advanced care directive forms, and issues concerning coroners and pronouncement of death.

#### **Overview of Hospice and Palliative Care**

The committee heard from various providers and stakeholders who described services included in hospice and palliative care. Stakeholders and providers who provided information to the committee included the Colorado Center for Hospice and Palliative Care, the Department of Public Health and Environment (DPHE), the Advanced Directive Consortium, the Center for Improving Value in Health Care (CIVHC), the Denver Hospice, chaplains, ethicists, coroners, physicians and nurses who provide palliative care, and other advocates in the community.

**Hospice care.** Hospice care is designed to treat pain and the symptoms of end-stage illness and provide care for individuals and families. Hospice care neither hastens or postpones the death of an individual, but rather focuses on quality of life for the individual and family members at the end of life. Hospice care services include developing a plan of care for individuals who are exhibiting end-stage illness, administering pain medication, and addressing the psychological and spiritual concerns of patients and family members regarding issues surrounding death. Hospice care can be provided in a home, a hospital, an assisted living facility, a nursing home, or a hospice residential unit. Hospice services can be paid by Medicare, Medicaid, private insurance, or a combination. In order to be eligible for hospice coverage under Medicare or Medicaid, a physician must verify that an individual has a six-month life expectancy prognosis. Data was presented to the committee which demonstrated that the average length of stay in a hospice in Colorado is 20 days, with the national average being 24 days.

**Palliative care.** Palliative care was described to the committee as the relief of physical and personal distress for individuals with a terminal illness or a chronic disease. Palliative care consultants aim to understand a patient's values and goals, manage their symptoms of illness or chronic disease, and coordinate care. Advocates indicated that palliative care is often administered through multi-disciplinary teams which include physicians, social workers, nurses, and spiritual personnel. Palliative care is an integrated care model that focuses on comfort and qualify of life versus a traditional care model that focuses on curative measures with a short period of time focused on death. Palliative care is offered by Kaiser Permanente, University Hospital, Children's Hospital, Memorial Hospital, the Exempla, HealthOne, and Centura hospital systems, and the Veterans Administration.

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### Barriers to Accessing and Utilizing Hospice and Palliative Care

The committee discussed several barriers to the access and use of hospice and palliative care. Specifically the committee discussed issues related to reimbursement of hospice and palliative care services and patient and family members' attitudes toward death.

**Reimbursement.** Providers indicated that the longer an individual requires hospice services, the better the provider is able to offset the costs of individuals who have no access to health insurance or public health programs. There was discussion among the committee that if the eligibility period for Medicaid hospice coverage was increased from six months to nine months, the length of stay in hospice care may increase, thus increasing reimbursement to hospices. In addition, providers indicated that increasing the eligibility period for hospice would save money by reducing hospitalizations, unnecessary prescriptions, and emergency room visits. As a result of this discussion, the committee recommends Bill C, which, pending federal approval, increases the eligibility period for the life expectancy prognosis from six to nine months for purposes of Medicaid.

Committee members heard testimony from several providers on ways in which the committee could implement administrative changes that would increase cost savings. Some of these changes include simplifying the billing process for reimbursement or allowing Medicaid to reimburse hospices directly for providing residential level of care for room and board in a hospice inpatient facility. As a result of these discussions, the committee recommends Bill E, which requires the Department of Health Care Policy and Financing, pending federal approval, to pay a nursing facility directly for inpatient services provided to a Medicaid recipient rather than paying the hospice care provider who then pays the nursing facility, thus reducing administrative burden and increasing administrative efficiencies.

*Fear of death.* One barrier to access discussed by the committee was an individual's fear to receive hospice services. Many advocates spoke to the fear that entering a hospice equates to a lack of hope or the notion that the person is "about to die." Advocates suggested that in many cases, individuals who received palliative care were more comfortable using palliative services because the focus is on quality of life, rather than the end of life. Many advocates spoke to the need to educate the public regarding the services provided to hospice and palliative care clients. Advocates also discussed educating physicians about how to approach the topic of advanced care planning. Providers noted that many physicians come from a "curative care" school of thought, meaning some find it difficult to discuss options outside of curative care.

## **End of Life Decisions**

Advanced care directives. The committee heard from several advocates regarding the definition and the appropriate use of the various advance directive forms. Advanced care directives forms are meant to allow "advance care planning" where individuals make decisions concerning medical decisions ahead of potential medical difficulties. Advanced care directives are not intended just for the terminally ill or those with chronic disease, but for any person who wants to see his or her wishes respected in times when he or she may be unable to make medical decisions. The committee heard about several different advance care directive forms. Each form has different requirements, such as a signature by a physician or advanced practice nurse, to be considered legal or valid by an emergency medical professional.

Advance care planning assumes that a competent adult or adult with decision-making capacity is making decisions. Some of the advance care decisions represented on the different forms include the right to refuse any treatment at any time for any reason, the right to determine

2	October 2009
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what types of treatment may be used when an individual is rendered incompetent, the right to determine when a person wants to be resuscitated, and the right to decide what happens to a person's body in case of death. Advanced care directive forms include:

- CPR directives;
- living wills;
- a Medical durable power of attorney;
- the Five Wishes form;
- the Medical Orders for Scope of Treatment (MOST); and
- the Physician Orders for Life Sustaining Treatment (POLST), the Medical Orders for Life Sustaining Treatment (MOLST), and the Physician Orders for Scope of Treatment (POST).

**Differences in the various forms.** Various stakeholders, including members from the CDPHE, the Colorado Advance Directive Consortium, and the Palliative Care Subcommittee of the Center for Improving Value in Health Care, testified to the committee regarding the pros and cons of each form. During committee, there was considerable discussion regarding which form was the most comprehensive, effective, and reflective of an individual's wishes, and the easiest to use. Committee members considered legislation that would have established the MOST form in Colorado law, however the legislation was withdrawn from consideration. As a result of these discussions, the committee recommends Bill B, which establishes a central on-line registry of advanced care directives, and Bill D, which updates the Colorado Medical Treatment Act.

**Declaring patients terminally ill.** During the 2008 legislative session, House Bill 08-1061 authorized advanced practice nurses (APNs) to sign certain documents, like disabled parking permits. Specifically, the bill authorized APNs to certify a terminal illness of a patient. According to testimony provided during the interim committee, APNs consider determining or certifying the terminal illness of a patient outside the scope of their practice. As a result of this discussion, Bill A, which reverts the statutory language changed by the passage of House Bill 08-1061 back to its original language excluding APNs' ability to certify a terminal illness, is recommended. Under the legislation proposed, solely physicians would have the authority to declare or certify a terminally illness.

#### **Coroners and Hospice Interactions**

The committee heard presentations from the Colorado Coroner's Association and various hospice providers regarding issues such as pronouncement of death, signing death certificates, the process in which the coroner is informed about a deceased hospice patient, and other issues. Hospice care providers testified that each coroner has a different procedure regarding pronouncement of death. Some counties require that a coroner investigate all deaths in a hospice, and some do not. Some coroners remove the deceased patient's medication or driver's license from the hospice setting, whereas others do not. Some hospices pre-register their patients with the coroner's office. Committee members discussed whether legislation was necessary to require that all coroners have the same processes in place regarding the legal pronouncement of death. Individuals testified that a "one size fits all approach" would not be effective in every county. Coroners and members of the hospice community agreed to work outside of the legislative process to address some of the issues surrounding pronouncement of death, who takes possession of medication, when to call the police, pre-registration, and other procedures.

## **Committee Recommendation**

As a result of committee discussion, the Interim Committee to Study Hospice and Palliative Care recommends five bills for consideration during the 2010 legislative session.

**Bill A** — **Declaring Patients Terminally III.** Bill A eliminates the ability of advanced practice nurses (APNs) to declare a patient terminally ill for the purposes of triggering end-of-life decisions and leaves such ability to the sole discretion of a physician. During the 2008 legislative session, House Bill 08-1061 authorized APNs to sign certain documents, like disabled parking permits. The bill also authorized APNs to certify a terminal illness of a patient. According to testimony provided in committee, APNs consider determining or certifying the terminal illness of a patient outside of the scope of their practice. Therefore Bill A reverts statutory language back to its original language prior to the passage of House Bill 08-1061 with regard to APNs' ability to certify a terminal illness.

**Bill B** — **On-line Registry Medical Directives Form.** Bill B requires the Department of Public Health and Environment to create and maintain an on-line registry of medical orders for scope of treatment (MOST) forms. Bill B allows individuals to electronically submit completed MOST forms to the registry and stipulates that physicians may access the forms with his or her national provider identifier number. Further, Bill B requires the department to implement appropriate data security measures to ensure confidentiality of the contents.

**Bill C** — **Medicaid Hospice Life Expectancy.** Currently, Colorado law requires a certified medical prognosis of life expectancy of six months or less for a patient to be eligible for hospice care under Medicaid. Bill C increases the life expectancy prognosis to nine months if the Department of Health Care Policy and Financing receives federal authorization to extend the time period.

**Bill D** — **Colorado Medical Treatment Act Update.** Bill D repeals and reenacts the Colorado Medical Treatment Decision Act, which outlines patient rights regarding medical treatment decisions. The act defines certain terms such as "artificial nourishment and hydration", "lacking decisional capacity," and "persistent vegetative state." Bill D affirms a patient's right to accept or reject medical or surgical treatment, and clarifies procedures by which an adult with decisional capacity may make decisions regarding one's health in advance of medical need.

**Bill E** — **Medicaid Hospice Room and Board Changes.** Bill E requires the Department of Health Care Policy and Financing to pay a nursing facility directly for inpatient services provided to a Medicaid recipient who is receiving hospice care, rather than paying the hospice care provider who then pays the nursing facility. Bill E stipulates that the change in reimbursement must be approved by the federal Centers for Medicare and Medicaid Services.