

# **THE COMMISSION ON END OF LIFE CARE**

Final Report

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January 2002

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The Commission on End of Life Care was staffed by the Minnesota Partnership to Improve End of Life Care and the Minnesota Department of Health.

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## FOREWORD

By Jan K. Malcolm  
Minnesota Commissioner of Health

Launching a policy discussion about any end of life issue is not an easy assignment.

The task is complicated, at the outset, by cultural norms that serve to discourage open discussion about this aspect of the human experience, by our lack of a common language and forum for discussing end of life issues, and by increasingly varied attitudes and beliefs about death and dying in a society marked by increasing cultural diversity.

The idea of providing appropriate comfort (palliative) care at the end of life also represents a departure from the underlying priorities and philosophy of our medical care system. In the ethos of medicine, the focus is on conquering – or at least controlling – the illness, and “losing” the patient tends to be regarded as a form of failure.

Despite these obstacles, we clearly need to look at how we go about providing care to people who are nearing the end of life. There is, first of all, a clear disconnect between what people want and what the system is providing. When asked, most people say they would prefer to spend their last days being cared for in their own homes, but most of the time that’s not what the system provides. Three out of four Minnesotans currently die in a hospital, a nursing home, or some other institutional setting.

We’re also currently devoting a lot of financial resources to end of life care, and it’s not clear that the money is being well spent. Right now, one health care dollar out of every 10 goes to provide care during the last six months of life. Often, those resources are used to support heroic but futile efforts to preserve life – efforts that often actually diminish the patient’s quality of life during those last precious months.

Changing demographics have heightened the urgency of addressing end of life care issues here in Minnesota. Our population is getting older, as well as more culturally diverse. By the year 2030, one Minnesotan out of every four will be over the age of 65. By 2050, Minnesota will be home to quarter of a million people over the age of 85, compared with about 90,000 today. Much of this growth will take place in our state’s minority populations and communities of color. By 2025, the number of people over age 65 will increase by 478 percent in the state’s African-American community, by 470 percent in the Asian-American community, and 769 percent in the Hispanic community.

In May 2000, our state’s health care and public health communities took an important step forward in addressing end of life care issues with the formation of the Minnesota Commission on End of Life Care. The Commission was a collaborative project of the Minnesota Department of Health and the Partnership to Improve End of Life Care, a private-sector group that includes Allina Health System, Blue Cross Blue Shield of Minnesota, Fairview Health Service, and HealthPartners. Organizations taking part in the project included health care provider groups,

professional associations, advocacy groups, faith communities, state agencies, education advocates, and the Minnesota Legislature.

The Commission was given a broad charge and an ambitious timeline. The group has examined end of life issues, including the impact of current regulatory policies that care, and the need for educating health care providers and the public alike.

The results of the Commission's work are contained in the following report. Obviously, a document like this one can never provide the final word on a set of issues as complex as those that surround end of life care, but this work represents a valuable beginning. We hope that our report will provide a valuable blueprint for reform – and for further exploration of end of life care issues. I want to offer my sincerest thanks to the Commission members for their work over the past eighteen months – and my enthusiastic encouragement to the many people in our community who must now play a role in putting these recommendations into action.

## EXECUTIVE SUMMARY

### MINNESOTA STATE COMMISSION ON END OF LIFE CARE: VISION

*Compassionate and competent care will be available, understandable, and accessible to all who are at the end of life. The diversity of cultural, spiritual, and religious beliefs will be treated with respect and sensitivity.*

## BACKGROUND

Due to the widespread and complex issues involved in improving care for people who are living with life-limiting conditions or who are dying, the Minnesota Commissioner of Health and the Minnesota Partnership to Improve End of Life Care collaborated to form the Minnesota State Commission on End of Life Care. The work of the Commission has focused on identifying the important issues and barriers to care, prioritizing those issues, and making recommendations for improvement. Recommendations from this report will help public and private policy-makers formulate improvements that will ensure all Minnesotans receive the best care possible at the end of their lives.

The Commission is made up of representatives from twenty-six organizations from the public and private sector as well as additional consultants. It has been staffed and financially supported by a grant from the Robert Wood Johnson Foundation Community-State Partnerships to Improve End of Life Care initiative.

## THE FINDINGS AND RECOMMENDATIONS

The Commission focused on the following four categories of end of life care issues:

<b>Guiding principles for care</b>	<b>Access to care</b>	<b>Education</b>	<b>Public policy</b>
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## GUIDING PRINCIPLES FOR CARE: THE FIVE GUIDING PRINCIPLES

Recognizing the need to create a framework for care at the end of life, the Commission developed the following guiding principles:

For those facing end of life care issues for themselves, their families, or their loved ones:

1. Preference for treatment and care will be discussed and respected.
2. Every reasonable effort will be made to relieve pain and other undesirable physical symptoms.
3. Emotional, spiritual, and personal suffering will be identified, addressed, and discussed.
4. Appropriate and realistic information will be provided regarding prognosis and the expected course of the events preceding death.
5. Grieving will be acknowledged.

## **ACCESS TO CARE**

Providers and communities should partner to ensure access to end of life services in Minnesota, with special attention to rural communities, minority and immigrant communities, children, and other potentially underserved populations.

### ***Rural Communities***

- Create education and development opportunities to strengthen hospice infrastructure
- Fund development of hospice programs in unserved areas
- Educate the public on end of life services and resources through locally based initiatives
- Educate physicians, nurses, and other health care personnel in hospice and palliative care

### ***Minority and Immigrant Communities***

- Develop informational materials for minority and immigrant communities
- Train medical interpreters and health care professionals who service these communities
- Develop, implement, and evaluate a cultural assessment tool for health care providers

### ***Children / Pediatric Communities***

- Develop a central resource for pediatric end of life care information

## **EDUCATION**

Community organizations, educational institutions and health care organizations will promote and support education in the areas outlined by the Five Guiding Principles.

### ***Community Organizations and the Public***

- Educate organizations that have access to a network or membership base (e.g. faith-based and other organizations) on such end of life topics as advance care planning, pain and symptom control, and hospice and palliative care
- Identify, develop, and maintain a catalogue of materials on end of life topics
- Distribute the Five Guiding Principles

### ***Health Care Organizations / Practicing Professionals***

- Support of the Five Guiding Principles by Minnesota health care providers
- Encourage hospice and palliative care certification for physicians, nurses, and other health care professionals

### ***Educational Institutions / Undergraduate and Graduate Education***

- Include curriculum based on the Five Guiding Principles in academic programming
- Fund further end of life care curriculum development and implementation through public and private sources

## **PUBLIC POLICY**

Public and private policy makers will promote and implement improvements in the areas of: 1) funding for residential end of life services; 2) out-of-hospital end of life care by emergency medical personnel; and 3) end of life care decisions for those who no longer have decision-making capacity and who have no other clearly identifiable decision-maker (adult orphans) or family.

### ***Residential End of Life Services***

- Pursue funding from new or reallocated resources to study removal of reimbursement barriers to hospice services, end of life services within assisted living, and end of life services within skilled nursing facilities
- Promote hospice and long-term care partnerships to explore alternative and innovative residential programs for end of life care

### ***Out-of-Hospital End of Life Care by Emergency Medical Services (EMS)***

- Develop standard and simplified vocabulary, policies, and portability for physician orders regarding cardio-pulmonary resuscitation (CPR) and comfort care to enhance understanding and implementation by EMS personnel responding to 911 calls at private residences and nursing homes
- Educate public and health professionals regarding use of out-of-hospital CPR and comfort care orders

### ***End of Life Care Decision Making for Persons without Designated Decision Makers (Adult Orphans)***

- Develop procedures within the health care systems (hospitals, clinics, skilled nursing facilities, etc.) to identify people who do not have responsible family members or other resources to make surrogate health care decisions
- Develop a system to assist those who do not have family or surrogate health care decision-makers to help them identify a health care agent (surrogate) or execute a health care directive
- Explore options for an expedited decision-making process that recognizes the need to make emergency comfort care or palliative care treatment decisions

## **NEXT STEPS**

The Commission has identified issues and made recommendations and strategies that will be the first step in improving end of life care. Minnesota now has a framework on which to build a better kind of care. However, the work of the Commission will only inspire change if leaders in the public and private sector support the recommendations and commit to putting them into action within their own organizations.

Next steps also involve engaging the public in understanding that they have choices and options for care at the end of life. This type of change must happen both on a personal and family level as well as a community level. For all who read this report and ask, “What can we do?” remember the words of Mahatma Gandhi: “We must become the change we want to see.”

# MINNESOTA COMMISSION ON END OF LIFE CARE

## BACKGROUND, STATISTICS AND HISTORY

### INTRODUCTION

If you ask people who live in Minnesota where they would like to receive care if they were dying, most would likely say, “I want to be at home.” A 1999 national survey reported that over 80% of the respondents preferred end of life care at home. Contrary to these wishes, 75% of Minnesota deaths occur in institutional settings (National Hospice Foundation, 1999).

We face an array of complex problems in trying to bridge the gap between the care that people would like to receive when they are dying and what they actually get. We live in a society that is not comfortable talking about death. Our health professionals are not well trained in providing end of life care. Care at the end of life is often costly, inappropriate, and provided in such settings as intensive care units or emergency rooms. Our medical payment system is designed to reimburse for procedures, tests, surgeries, and hospitalizations aimed at curing disease rather than providing comfort when cure is no longer possible.

In order to address these issues, the Minnesota Commissioner of Health and the Minnesota Partnership to Improve End of Life Care joined to form the Minnesota Commission on End of Life Care. The Commission met for over a year and a half to study the barriers and challenges to providing high-quality, compassionate, and accessible care to people at the end of life.

### END OF LIFE CARE IN MINNESOTA

#### Minnesota Death Statistics

One way to anticipate which populations are more likely to require end of life services is to examine the demographics of Minnesotans who have already died. The following data was collected from all death certificates filed with the Minnesota Department of Health for the year 1999 (the most recent year all records were available). See Appendix 5 for more detailed data.

#### Number of deaths by age

80% of deaths occur in people over the age of 65. It is estimated that in the year 2030, one out of every four Minnesotans will be over age 65, compared to one out of every eight today. By 2050 250,000 Minnesotans will be over age 85, compared to 90,000 today (MN DHS, 1998). 1999 the ages of people who died were:

Age Group	Percent of Deaths	Number
0 – 1 year old	1.1%	409
1-19 years old	1.1%	424
20 – 64 years old	18.1%	6,988
65 – 84 years old	45.4%	17,490
85 and older	34.3%	13,227
All ages	100%	38,538

### Number of deaths by diagnosis

In 1999 heart disease, cerebrovascular disease, and cancer accounted for two-thirds of all deaths in Minnesota. The leading cause of death in 1999 was major cardiovascular disease, which accounted for 35.6% of all deaths. The table below lists the primary causes of death in Minnesota.

Diagnosis	Percentage of deaths	Total Number of Deaths
Major cardiovascular disease	35.6%	13,683
Cancer of all types	23.1 %	8,876
Cerebrovascular disease	7.8%	2,983
Violent deaths (suicide, homicide, injuries, etc.)	6.4%	2,449
Other causes	27.1%	10,547

### Number of deaths by location

Death certificates indicate whether death occurred at a hospital, nursing home, residence, or other location. The “hospital” indicator includes those individuals who were determined to be dead on arrival, those who died in the emergency room, and those who died during an inpatient hospital stay. “Nursing home” includes both deaths among residents of the nursing home. The “other” category includes psychiatric facilities, prisons, and residential hospices.

#### *Deaths by location*

Deaths in the hospital	34.4%	(13,259)
Deaths at a nursing home	42.8%	(16,479)
Deaths at home	20.3%	(7,804)
Other or unknown	2.5%	(996)

### Numbers of home deaths by county

The rates of death at home varied considerably across the eighty-seven counties in Minnesota. The range of rates of home death in 1999 was 8.3% in Rock County to 34.1% in Clay County. Despite wide variation across all counties and even among similar sized counties, a trend emerges related to the number of deaths in a county and the rate of death at home. Counties with smaller numbers of total deaths in 1999 had relatively fewer deaths at home, compared to counties with more deaths. Even within the seven-county Twin Cities metropolitan area, rates of death at home varied considerably. These rates were:

#### *Percentage of deaths at home in the 7 county Twin Cities area*

Anoka County	Carver County	Dakota County	Hennepin County	Ramsey County	Scott County	Washington County
31.5%	23.2 %	26.4%	21.2%	22.3%	27.6%	29.8%

**Analysis**

In order to provide high quality end of life care to the populations that need it most, it is useful to examine where people die, what they die of and where they live. The Commission used the 1999 data offered here as a reference to determine where the needs in end of life care are, and the gaps that exist in the current distribution of services.

**PROVISION OF CARE IN MINNESOTA**

Minnesota has a large number of facilities, providers, and institutions that deliver care. The Department of Health’s web site (<http://www.health.state.mn.us>) details the variety of the state’s facilities:

<b>Type of Facility</b>	<b>Number</b>
Licensed hospice providers	79
Licensed hospitals	140
Licensed nursing homes	431
Home care providers	829
Housing with services facilities (example: assisted living facilities)	621
Boarding care homes	62

**Palliative care**

Palliative care involves treatment and care that is focused on providing comfort by relieving pain and other symptoms. Only two hospitals in Minnesota have formal, supported palliative care consult teams. Several other hospitals are in the process of developing similar programs for their patients. In addition to the hospital palliative care teams, four home-based health care programs support palliative care services or consultations.

**Hospice care**

Hospices are currently the most widely available programs designed specifically to care for people who are dying. Hospice services are available throughout Minnesota and paid for through the Hospice Medicare Benefit, Medicaid, and private insurers. In 1999 only 18% of Medicare patients who died in Minnesota received hospice services (GAO, 2000). While the Medicare Hospice Benefit and a majority of other similar hospice benefits are intended to pay for six months of hospice services, patients are often referred to hospice programs very late in their illnesses. In 1997 the median length of stay in a hospice program in Minnesota was thirty-four days, and 19% of admitted patients died within seven days of their enrollment (MHO, 1999). Hospice programs are typically home-based programs designed to help patients die in their homes. However, five licensed residential hospice facilities in Minnesota provide hospice care in a home-like setting.

### **Education – Undergraduate and Graduate**

Minnesota has three medical schools: the Mayo Medical School, the University of Minnesota Medical School – Twin Cities, and the University of Minnesota - Duluth School of Medicine. In addition, Minnesota has approximately sixteen universities that offer baccalaureate nursing degrees and several others that offer associate degrees in nursing. The University of Minnesota, Twin Cities has the only college of pharmacy in the state. A multitude of colleges and universities offer social work and psychology programs, however curriculum addressing end of life care is varied, often fragmented, and in some cases absent.

### **Education—Practicing Professionals**

Practicing health care professionals who are certified in hospice and palliative medicine offer an expertise that can be beneficial to patients at the end of life. A national testing system provides certification for physicians and nurses and assures competency in providing comfort care. Of the 15,000 registered physicians in Minnesota twenty-one are currently certified in palliative care. Of the 58,000 registered nurses in the state, 159 have palliative care certification.

### **Health Care Directives**

Minnesota has one of the most advanced health care directive laws in the country. Revised in 1998, the law allows a person either to write down their personal care wishes in advance or choose someone who can make health care decisions for them at the end of life (most often referred to as the “health care agent”). Despite the progressive nature of Minnesota’s health care directive law, few people actually complete a health care directive. A 1996 study of Minnesota hospitals, nursing homes, and home care agencies estimated that fewer than 10% of patients admitted for care had a completed an advance directive (Stum & Ross,1996).

### **Cost of Care**

Data on the cost of caring for people at the end of life is scarce. A 1996 national study estimated that end of life care consumes 27% of the Medicare budget (Emanuel, 1996). Payments for patients in the last six months of life totaled \$103,525,666 for Minnesota Medicaid patients in 1999. The average payment for a patient’s final hospitalization was \$13,446 (DHS Raw Data, 2000). Medicare data show that 23.1% of Medicare patients in the Minneapolis region experienced intensive care during the last six months of life (Dartmouth Atlas, 1998).

Cost of care includes expenses incurred by families. Nearly one-half of all bankruptcies filed in the United States by people over the age of 65 are attributed to medical reasons, (Warren et al., 2000). A 1999 study estimates that caregivers lose approximately \$659,000 in wages and benefits and that informal caregiving costs American businesses up to \$11.29 billion annually (MetLife, 2000).

### **Health Care Coverage**

All major insurance plans in Minnesota include a hospice benefit. While coverage under this benefit usually mirrors coverage under the Medicare Hospice Benefit, plans vary in scope and eligibility. Hospice care is also covered under Medicaid and the state-supported insurance plan Minnesota Care. Current insurance plans do not cover palliative care consultation or follow up unless it is done by a physician or occurs under the skilled home care benefit.

### **Out-of-Hospital End of Life Care by Emergency Medical Services (EMS)**

Minnesota supports out-of-hospital “Do Not Resuscitate” (DNR) physicians orders. DNR orders help prevent unwanted cardio-pulmonary resuscitation by paramedics and emergency transport personnel. While Minnesota supports DNR orders, the implementation policies and procedures vary among the different ambulance transport systems. Currently, Minnesota has about 300 ambulance transport systems.

## **THE COMMISSION ON END OF LIFE CARE**

The Commission was co-sponsored by the Minnesota Department of Health and Minnesota Partnership to Improve End of Life Care with funding from the Robert Wood Johnson Foundation. Each co-sponsoring organization brought a unique perspective to end of life care leading to creative dialogue, unique approaches to problem solving, and a wider sphere of influence.

### **Minnesota Department of Health**

The Minnesota Department of Health (MDH) is the state's leading public health agency, legally charged with "protecting, maintaining, and improving" the health of the state's citizens. Major program areas at MDH include the prevention and control of chronic and infectious diseases, health economics and health care policy, elimination of health hazards in the environment, maternal and child health, and implementation of strategies for promoting healthy behavior choices.

In addition, MDH is responsible for regulating managed care organizations, hospitals, nursing homes and other long term care facilities, home care providers, and hospice providers. MDH maintains programs to address the health issues surrounding Minnesota's refugee and immigrant populations. During the last legislative session, MDH received a two-year, \$14 million appropriation to address disparities in health status that affect the state's minority communities and populations of color.

### **Minnesota Partnership to Improve End of Life Care**

The Minnesota Partnership to Improve End of Life Care was founded in 1999 by Allina Health System, HealthPartners, and Fairview Health Service with Blue Cross Blue Shield of Minnesota. Under the financial management of the Metropolitan Area Agency on Aging, and with funding from the Robert Wood Johnson Foundation, the Partnership has worked to raise the standards of end of life care.

During its first two years of activities, the Partnership focused on three areas:

- Focus Area 1:*** Improving public policy and increasing public awareness on end of life issues
- Focus Area 2:*** Improving and promoting education for health professional students, practicing professionals, and consumers
- Focus Area 3:*** Improving reimbursement for end of life care

### **Minnesota Commission on End of Life Care**

The Commission on End of Life Care consisted of representatives nominated from a variety of organizations, and jointly appointed by Commissioner of Health Jan Malcolm and the Minnesota Partnership to Improve End of Life Care (for complete list of participating organizations and their representatives see Appendix 1). The Commission was established as an eighteen-month, time-limited project beginning in May 2000. The meetings were lead and staffed by both the Partnership and the Department of Health. Commission meeting minutes can be found at the Minnesota Partnership to Improve End of Life Care website - [www.minnesotapartnership.org](http://www.minnesotapartnership.org).

All Commission work and recommendations were based on a consensus model of decision-making. During the first meeting, Commission representatives used consensus voting to identify and validate the following issues (listed in the end of life issues box below).

***End of Life Issues***

Barriers to dying at home  
Late enrollment into hospice care  
Inconsistent institutional care  
Inconsistent emergency transportation standards  
Lack of certified palliative care health professionals  
Lack of end of life education for health professionals  
Loss of caregiver services through state programs with enrollment into hospice  
Inconsistent end of life data  
Expense of end of life care

At subsequent meetings the problems listed in the box above were consolidated into four issue areas. Sub-committees then formed to work on the problems unique to each issue area, identify specific barriers, and make recommendations for improvement.

Although a variety of concerns were discussed among sub-committees in each issue area, not all of them were brought forward for recommendation. As Commission co-chair Dr. Barry Baines said, “We can do anything. We can’t do everything.” While all of the issues raised were considered important and worthy of consideration, the Commission was forced to focus on the issues that were within the scope of the Commission’s directive and influence. Issues identified by the Commission but not brought forward for recommendation are listed in Appendix 2. The following criteria helped Commission members determine which issues to focus on:

***Criteria 1***

Is the problem within the scope of the state and the organizations represented to make changes? For example, issues regarding federal legislation and federal regulation, such as Medicare barriers were considered outside the scope of the Commission.

***Criteria 2***

Is the problem defined and documented well enough to make a concrete recommendation for improvement? For example, inability of patients to obtain opioids at some neighborhood pharmacies could not be confirmed as a significant problem.

***Criteria 3***

Is the scope of the problem larger than end of life care? Issues such as the nursing shortage that encompasses the entire health care field were not pursued.

As part of the Commission work, the Minnesota Partnership to Improve End of Life Care conducted three projects to gather data for further information. The first project consisted of interviews with key informants from minority and immigrant communities about end of life issues. The second project involved four roundtable discussions on end of life care needs in communities outside the Twin Cities metro area. Documentation of these two projects are found in the recommendation section of this report. In the third project, data from death certificates over the past ten years were analyzed to identify trends in diagnosis and place of death. Results of this project are printed under the “Minnesota’s death statistics” heading in this section and in Appendix 5.

The Commission would like to acknowledge the valuable assistance it received while conducting the three projects from members of the community who were not Commission representatives. In addition to project assistance, many individuals from a wide variety of organizations provided input and suggestions from sub-committee meeting attendance to offering advice on the issues. See appendix 3 for a list of people who assisted the Commission and staff.

**SUMMARY**

The Minnesota Commission on End of Life Care was created because significant gaps exist for people who are facing the end of life. The Commission identified and prioritized the issues that cause the most significant barriers to accessing the best care. After analyzing interviews conducted by staff, data about the number of Minnesotans who die and the particulars of their deaths, and the composition of the health care system, the Commission arrived at recommendations for improving end of life care. The remainder of this document is a detailed listing of these recommendations and strategies for their implementation.

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# **GUIDING PRINCIPLES FOR END OF LIFE CARE**

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# STATEMENT OF THE GUIDING PRINCIPLES OF END OF LIFE CARE

## INTRODUCTION

Hospitals, skilled nursing facilities, clinics and home care agencies have varied standards and expectations regarding the care of someone who is dying. In Minnesota and the rest of the nation, end of life care across health care settings is inconsistent. A patient in hospital X might receive excellent pain management, spiritual care, and family support, while a patient in hospital Y receives mediocre pain management and no other support services. The one exception to this inconsistency is hospice care, which is regulated at both the state and federal level. Hospice programs follow a prescribed list of care standards including expert symptom management, interdisciplinary care for spiritual and personal/family needs, and other support services.

The Commission believes that a high quality level of care should be established for end of life patients regardless of the setting in which they receive their care. Rather than suggesting specific standards for each health care facility or agency, the Commission decided to create a framework of care that could be used by health care providers, patients, and families alike. These Guiding Principles emerged through small and large group discussion. The principles were based on the following premises:

- Each principle reflects reasonable expectations that every Minnesotan should have regarding participation in care decisions, pain and symptom assessments, treatment of undesirable symptoms, and grief and bereavement care.
- The principles mirror a reasonable level of care that can be expected of a concerned, caring, and sensitive health care system. The Guiding Principles are written to be appropriate for health care systems of every size, scope, and location.

The Guiding Principles represent a synthesis of resources. They include hospice standards of care from the National Hospice and Palliative Care Organization (NHPCO), palliative care precepts developed through the *Last Acts* organization, the Seven Promises of *Americans for Better Care of the Dying*, Joint Commission standards on pain management, and other resources. Each principle is written both from the perspective of the health care system and from the perspective of people facing the end of life along with their loved ones. The principles are preceded by two inclusive statements, which were written to reflect the intention of the Commission that the Guiding Principles apply to all patients in all settings.

The Five Guiding Principles for End of Life Care appear in entirety on pages 20 and 21.

## NEXT STEPS

The Guiding Principles define the best practices in end of life care. The public, health care providers, health care organizations, and community organizations must be engaged to promote awareness, support, and commitment to these principles. The recommendations put forth by the Commission will identify ways to close the gap between current knowledge and the best practice in end of life care.

## **FIVE GUIDING PRINCIPLES FOR END OF LIFE CARE**

COMPASSIONATE AND COMPETENT CARE WILL BE AVAILABLE,  
UNDERSTANDABLE, AND ACCESSIBLE TO ALL WHO ARE AT THE END OF LIFE

THE DIVERSITY OF CULTURAL, SPIRITUAL, AND RELIGIOUS  
BELIEFS WILL BE TREATED WITH RESPECT AND SENSITIVITY.

For those facing end of life issues for themselves, their families or loved ones:

### **1. PREFERENCE FOR TREATMENT AND CARE WILL BE DISCUSSED AND RESPECTED.**

Individuals and their families can expect:

- To be informed of choices and options, to be listened to with compassion, and to participate in decisions about care
- To have questions answered in a way that can be understood
- To have a written plan of care with specified health care directives respected.

To facilitate these preferences, health care providers (such as physicians, nurses, hospitals, social workers, nursing homes, hospices, home care agencies, and other health care providers and organizations) should:

- Ask about goals and preferences
- Include individuals and their loved ones in the care decision process, whenever possible
- Provide assistance and resources to formulate advance care plans
- Honor written health care directives

### **2. EVERY REASONABLE EFFORT WILL BE MADE TO RELIEVE PAIN AND OTHER UNDESIRABLE PHYSICAL SYMPTOMS.**

Individuals and their families can expect:

- Reports of pain and other symptoms to be believed
- Informed, competent, and compassionate pain and other symptom relief
- Urgent treatment of such severe symptoms as pain and/or breathlessness

Providers should:

- Use available tools to assess pain and believe reports of distress
- Make reasonable efforts to anticipate, prevent, and relieve undesirable symptoms
- Treat severe symptoms immediately

**3. EMOTIONAL, SPIRITUAL, AND PERSONAL SUFFERING WILL BE IDENTIFIED, ADDRESSED, AND DISCUSSED.**

Individuals and their families can expect:

- To be asked about and offered relief of emotional, spiritual, and personal suffering
- Respect for cultural and religious preferences

Providers should:

- Ask about emotional, spiritual, and personal suffering
- Offer the help of interdisciplinary and/or community resources

**4. APPROPRIATE AND REALISTIC INFORMATION WILL BE PROVIDED REGARDING PROGNOSIS AND THE EXPECTED COURSE OF EVENTS PRECEDING DEATH.**

Individuals and their families can expect:

- To be prepared for changes that are likely to occur in the course of an illness
- A plan to be in place for managing anticipated events
- To be informed about the costs of treatments and care

Providers should:

- Provide honest information on what is likely to happen in the course of an illness
- Provide guidance in planning how to handle predictable events
- Identify patients who are likely to die from their current illness and make a plan congruent with that outcome

**5. GRIEVING WILL BE ACKNOWLEDGED.**

Families can expect:

- Compassionate acknowledgment of loss in a quiet and safe place
- To be with the deceased loved one as long as needed/desired
- Compassionate recognition that grieving takes time
- Acknowledgement that grief and loss can begin prior to death and may continue for longer than “expected”
- Understanding that every death and every family member’s response to that loss is unique
- To receive a minimum standard of bereavement follow-up after the death.

Providers should:

- Provide a quiet and safe place for families to grieve
- Accommodate family wishes to be with the deceased loved one
- Acknowledge that grieving is a unique process with a variable time course
- Offer options for support for long-term grieving
- Acknowledge that grief and loss begin prior to death and may continue longer than “expected”
- Provide an accepted standard of bereavement follow-up after the death



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# **INTRODUCTION TO RECOMMENDATIONS SECTION**

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## INTRODUCTION TO RECOMMENDATIONS SECTION

The following section contains the background for the recommendations and strategies for implementation. The recommendations are divided into three issue areas:

### **Access to end of life care and services**

Pediatric, rural populations, and minority and immigrant communities

### **End of life education**

Public, undergraduate and graduate students, and practicing professionals

### **End of life public policy**

Residential end of life care, adult orphans, and out-of-hospital end of life care by Emergency Medical Services (EMS)

A fourth Public Policy recommendation regarding nurse practitioners' ability to refer to hospice and bill for services for hospice patients is covered in Appendix 4. Because this is an issue of federal regulation, the Commission opted to write a letter of support to the National Hospice and Palliative Care Organization supporting legislation to revise the rules regarding nurse practitioners and hospice care.



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**ACCESS TO END OF LIFE  
CARE AND SERVICES  
RECOMMENDATIONS**

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# **ACCESSING END OF LIFE CARE AND SERVICES**

## **PEDIATRICS**

### **INTRODUCTION**

One of the greatest losses for an individual and the community is the death of a child. When children face life-limiting illnesses, the health care system, the family, and the community will most likely do anything and everything to preserve their lives. Despite these efforts, children still die, and they often do so without the benefit of hospice or palliative care, which could ease their suffering.

### **PEDIATRIC END OF LIFE CARE IN MINNESOTA**

In 1999, 409 infants under the age of one and 424 children between the ages of one and nineteen died in Minnesota. For infants, the leading cause of death was attributed to conditions originating during the perinatal period. Accidents were the leading cause of death for those over one year, followed by suicide, malignancies, homicide, heart disease, and congenital anomalies (Minnesota Department of Health, n.d.). For children with life-limiting illnesses end of life the expertise and resources are scarce in Minnesota and include only one pediatric focused hospice program.

Interviews and discussions conducted by Partnership staff with health care professionals and community members in both the metropolitan area and greater Minnesota indicate a strong need for palliative care resources for children. Interviewees and discussion participants identified increased services, education, and resources for pediatric end of life care as an area of health care that needs improvement.

### **SPECIAL NEEDS OF CHILDREN**

While the numbers are small, provision of high-quality end of life care for children is problematic for a number of reasons (ChIPPS, 2000):

- The developmental age of the child affects the way treatment, the disease process, and death are approached by health professionals.
- The verbal skills of the child may be limited, making pain and symptom assessment and management difficult.
- Many children receive very aggressive technological interventions in hopes of prolonging life and finding a cure.
- Often siblings are involved and their care adds additional stress to overtaxed parents and family members.
- Parents must make the ultimate decisions on treatment, which can cause difficulties and emotional distress if the child does not agree with the parent.

As in the care of adults who are dying, the medical reimbursement system favors aggressive and curative treatment. It's easier to obtain coverage for a test or procedure than to obtain coverage for a therapeutic discussion with parents about palliative care options.

The inadequacy of pediatric palliative care has been documented in a number of studies. In a recent study of 103 children who died of cancer, researchers determined that 89% of the children suffered "a lot" or "a great deal." They also found that treatment for pain was successful only 27% of the time (Stephenson, 2000). Hospice care is not utilized often for children. In fact, only 1% of children with life-limiting illnesses receive hospice care (Stephenson, 2000).

Often health care providers are not adequately trained for pediatric end of life care. In a 1998 survey of 228 pediatric oncologists, 91% stated that they learned to care for dying children through trial and error on the job. Only 2.2% said they had a hospice or palliative care rotation during their schooling (Hilden et al., 2001). Pediatric oncology nurses and physicians often express misgivings about their abilities in communicating with children at the end of life, discussing advanced directives with families, and relieving pain and other symptoms (Duncan et al., 2000).

Experts emphasize the need for a definition of the end of life for children. Families have stated that the time of crisis for a child with a life-limiting illness is the point of diagnosis (Stephenson, 2000). This is when the most emotional issues arise and when questions of treatment and payment options are most confusing and challenging.

"Children need time to prepare for death, too."

~ *Chaplain from Rochester's Mayo Clinic*

The Children's International Project on Palliative/Hospice Services (ChIPPS) identified three principles of pediatric palliative care. The principles are similar in intent and content to the Five Guiding Principles for End of Life Care with a few provisions specific to children (ChIPPS, 2000):

***Principle 1***

Palliative care programs should not require a short-term prognosis of death, but merely the criteria that the child will not survive to adulthood.

***Principle 2***

Children and their families are the unit of care and they should have access to a consistent interdisciplinary team of caregivers twenty-four hours a day every day.

***Principle 3***

Families should be able to refer themselves to a pediatric hospice or palliative care program.

## **RECOMMENDATIONS AND STRATEGIES**

### **Central Resource Center**

Health care organizations that care for children and their families when a child has a life-limiting illness should provide appropriate services and resources in conjunction with the Five Guiding Principles to Improve End of Life Care and the Universal Principles of Pediatric Care. In an effort to achieve improved care, people knowledgeable on pediatric issues should help facilitate and implement the creation of a central pediatrics palliative care resource center in Minnesota, using public and private funds. The resource center should provide:

- Telephone consultation services for health professionals, including doctors and nurses
- Information for parents and family on care and resources
- Information for health professionals on care and resources
- Education opportunities for student and practicing health care professionals

In addition, the Commission recognizes the need for comprehensive insurance coverage that includes adequate reimbursement for interdisciplinary palliative care and palliative care consults.

### **SUMMARY**

Improvements in the care of children should come from both the health care organizations through increased and better prepared interdisciplinary pediatric palliative care teams, as well as from the community via funding for a central resource on pediatric end of life care.

# ACCESSING END OF LIFE CARE AND SERVICES

## RURAL ACCESS

### INTRODUCTION

Helping dying patients to stay at home and providing high-quality end of life care is challenging in rural areas. Hospice programs that could help patients to remain in their homes do not cover all of Minnesota, and many rural hospice programs struggle financially because of the small numbers of eligible patients. A number of rural areas face a shortage of doctors, nurses, and other health care providers. In addition to a shortage of professional caregivers, rural Minnesota suffers a shortage of family and informal caregivers as, an increasing number of young people leave the rural areas for urban settings.

### COMMUNITY ROUNDTABLE DISCUSSIONS

“I had no information or awareness of services in this area and I’ve lived here for years. Information must be made known!”

~ *Community roundtable participant*

To better understand the problems regarding end of life care outside the Twin Cities metropolitan area, Partnership staff conducted four regional “Roundtable Discussions.” The discussions were held in Breckenridge, Little Falls, Duluth, and Rochester and were hosted by such local community members as the local hospice program and the regional Area Agency on Aging. Altogether, over one hundred people participated in the discussions, including physicians, nurses, social workers, chaplains, senior citizens, local government officials, funeral directors, and clergy.

The discussions produced a wide range of information regarding care issues and the needs of each community. The discussions focused around the issues of education, access to end of life care, and public policy.

### Education

All groups identified a strong need to educate community health care professionals, including doctors and nurses, on end of life care. The education needs identified included:

- ***Communication***  
Improving communication with patients and families; as one physician noted, “Doctors are some of the worst communicators when it comes to talking about dying.”
- ***Pain and symptom management***  
Improving pain and symptom management skills; a nurse said, “Many nurses don’t know the basics of pain management—simple things like putting a patient on a regular pain relief schedule or always combining a bowel program with the use of morphine.”

- ***Hospice referral***

Understanding hospice and when to refer; a hospice manager commented, “Like many programs, we get referrals so late we hardly have time to see the patient.”

Public and community education was also identified as a need. Areas for improvement included:

- ***Hospice Care***

Increasing public awareness about hospice care; a community participant pointed out, “Many people don’t know we have hospice around here.”

- ***Health care directives and advance care planning***

Increasing public awareness about health care directives and advance care planning; as a senior community member said, “We don’t know where to go to find out about this.”

- ***Religious leaders***

Increasing community clergy skills and comfort in dealing with dying people; one participant commented, “When my wife died, my minister didn’t know what to say to me. I felt abandoned.”

Suggestions for improving health professional education centered on creating local opportunities to educate physicians and nurses. Public education included use of community clergy, parish nurses, and funeral directors as well as the continuing role of hospice programs in raising public awareness.

### **Access to End of Life Care**

The ability to access high-quality end of life care was identified as a significant issue. A number of concerns were articulated specific to rural areas:

- ***Distance***

The further a patient lives from a populated area, the more difficult it is to receive services at home.

- ***Lack of informal and professional caregivers***

A public health nurse commented, “In our region, many of the children have moved away. When someone is old and frail, they have no one to take care of them.”

- ***Out-of-area physicians***

many patients see physicians in metropolitan areas and are not referred back for services in their community when they need them. In addition, the out-of-area physician may not communicate well with the local physician.

- ***Pediatric populations***

Pediatric palliative care is problematic both because of insurance issues and the lack of knowledge and resources to care for dying children. A nurse stated, “We need a central resource we can call with questions about pediatric palliative care.”

Minority and immigrant population access issues were also identified. Problems discussed included:

- Lack of skilled medical interpreters
- Lack of advocates in the community to help people access services
- Lack of translated materials and tools

## **RECOMMENDATIONS AND STRATEGIES**

Recommendations for addressing geographical disparities in end of life care center on two issues: hospice and improved education.

Providers and communities should partner to ensure access to end of life services:

- Create education and development opportunities to strengthen hospice infrastructure. Strategies include hospice management workshops to help hospice leaders expand access, understand finances, and explore the benefits of building coalitions.
- Fund the development of hospice programs in unserved areas. Strategies include public and private grants and local fund-raising initiatives.
- Educate the public on end of life services through locally based initiatives. Strategies include training information and referral personnel from Area Agencies on Aging and county workers on hospice benefits and other resources.
- Educate physicians, nurses, and other health care personnel in hospice and palliative medicine. Strategies include development of local and regional education opportunities.

## **SUMMARY**

Minnesotans in rural and sparsely populated areas have less access to high-quality end of life services, including hospice care. Distance, fewer resources, and a decreasing number of family caregivers contribute to the problem. Local health care professionals, such as doctors and nurses, are not always proficient in end of life care, nor do they have the educational opportunities to increase their skills. Recommendations for improvement include strengthening current hospice capabilities, and increasing funding to expand hospice programs into currently unserved areas. In addition, communities should partner to increase public awareness of end of life resources and train health care professionals in end of life care.

# ACCESSING END OF LIFE CARE AND SERVICES

## MINORITY AND IMMIGRANT POPULATIONS

### INTRODUCTION

The ethnic and cultural makeup of Minnesota is constantly changing. Persons from different backgrounds, cultures, and ethnicities have a variety of health care needs, particularly near the end of life. Health care providers who approach patients in a culturally-sensitive way can help to ease the distress of dying patients and their families (Sheikh, 1998).

### MINORITY AND IMMIGRANT COMMUNITIES IN MINNESOTA

Minnesota's elderly minority and immigrant population is growing. By the year 2025, the number of African Americans over the age of 65 will increase by 478%, Asian Americans by 470%, and Hispanic Americans by 769% (MN DHS, 1998).

The composition of Minnesota has changed over the last ten years. The majority population of non-hispanic whites has decreased from 93.7% in 1990 to 88.2% in 2000. Nearly 200,000 African Americans 140,000 Asian Americans, 130,000 Latino or Hispanic and 55,000 Native Americans persons live in Minnesota. (US Census Bureau, 2001) 1999 death certificate data indicate that 2% of the deaths in the state were African Americans; 1% Asian, and 1% Hispanic.

### CROSS-CULTURAL INTERVIEWS ON END OF LIFE CARE

The staff of the Minnesota Partnership to Improve End of Life Care conducted interviews with fourteen representatives of minority and immigrant communities to gather information on cross-cultural end of life issues for the Commission on End of Life Care. Health Advocates, a cross-cultural consulting organization, helped to organize and conduct the interviews. Those interviewed included members of African American, Native American, Hispanic, Hmong, African, Asian and Eastern European communities. The people interviewed encompassed a variety of professions, including medical doctors, religious leaders, nurses, chaplains, community advocates, and consumers.

#### ***Questions for Minority and Immigrant Community Representatives***

What is your community's idea about what the last stage of a person's life should be like?

What assistance from United States health care would help in providing this kind of care for a person in your community?

What problems do you know about for people in your community in receiving the best end of life care?

What are the most important things health care providers should know about end of life care in your community?

What should be done to plan for and create better health care systems for people in your community at the end of their lives?

## FINDINGS

Persons of diverse ethnic and cultural backgrounds generally prefer to have health care providers ask them about their beliefs and attitudes. Our cross-cultural interviews revealed several findings including the following:

- Some cultures have a strong belief in preserving the body through the use of aggressive treatment.
- Some cultures view death as a natural and important time of life and believe that pain and suffering should not necessarily be avoided at such times.
- Some cultures take a holistic approach to health care in general and prefer to treat the “whole person” as opposed to a disease or illness within the person.

For most cultures, a good death involves remaining at home surrounded by family and friends. Some patients may fear the hospital and other institutions and prefer to receive care from those who love them. Hospice services are acceptable to most cultures as long as they are sensitively delivered with respect to the individual’s beliefs and values.

“Families are very close and extended. The community really cares for its own, and most people prefer to die in their own homes with their family there to give care.”

~ *Latino interviewee*

### Grief

Grieving varies not only within cultures but on the individual level as well. Some cultures have specific grieving practices and beliefs that the community generally adheres to. For example, within the Hmong community grieving and funeral activities take place twenty-four hours a day for a week after a person dies. After the week of mourning ends, so does the expression of grief. Some beliefs about the end of life and life after death, such as reincarnation, affect grieving and the amount of time a person will grieve publicly over a loved one.

### Trust and respect

Discrimination still occurs on many levels for many minority and immigrant individuals. Interviews within every culture stated that respect and equal treatment are desired from the health care system.

“Hispanic people want to die with dignity and to be respected as human beings and treated the same as everyone else.”

~ *Latino interviewee*

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The lack of professionals from minority and immigrant communities was identified by nearly all cultural groups as a problem that affects a person's trust in the health care system. Many cultures would prefer to have health care provided by a person of a similar ethnic or cultural background.

A general mistrust of Western medicine exists in some cultural groups. The size and nature of health care systems today often prevent the formation of relationships between health care providers and patients. Personal relationships were identified by some interviewees as vital in attaining trust in the health care provider and Western medicine as a whole. Other interviewees said their community generally has a high level of trust in the United States' health care system, believing that Minnesota's providers are very compassionate towards persons without insurance.

### **Religion and spirituality**

Religion and spirituality are important to some cultures in general and to many individuals specifically at the end of life. Individuals prefer to be asked about their religious or spiritual preferences by their health care provider.

“A devout Muslim believes that your life is entrusted to you by God and that you should do everything in your power to preserve it.”

~ Somali interviewee

### **Decision-making**

Western cultures place emphasis on individual autonomy when it comes to making decisions. Many cultures do not approach decision-making in this way. In some cultures, decisions are not made on an individual basis. For some patients, health care options may be decided through an elder male within a family such as a father, husband, or son. For other patients, decisions might be made through a community framework in which certain members of the extended cultural community, such as a religious leader or community elder, are called upon to make decisions for or with a patient.

“Talk to the family without the patient present – talking to the patient will only cause them to become depressed. The clan will make their decisions for them with the doctor.”

~ Hmong interviewee

### **Communication with patients and families**

Telling a patient they are going to die or openly and frankly discussing death and dying with a patient and their family is considered inappropriate in many cultures. Beliefs range from, “What good would it do to tell someone they're dying?” to, “Telling someone they will die will cause depression and prevent them from getting well.” Some cultures prefer not to discuss the possibility of death at all. Other cultures might have family members openly discuss death and

dying with health care providers but shield their loved one from the frankness of the discussion. Even though patients and families from minority and immigrant cultures often do not want to discuss death and dying, they still want to be informed of the seriousness of their illness and treatment options in a culturally-sensitive discussion.

Interviewees identified the lack of trained medical interpreters as a serious problem. Interviewees noted that health care providers often seem reluctant to use interpreters and providers sometimes rely on the patient's family members to translate for them.

Explanations of illness progression, prognosis, and treatment options are often not understood by patients. Words like "metastasize," "10% survival rate," "stage four," and "failed therapy" represent common medical language that could be interpreted in multiple ways by a patient. This problem is not restricted to minority and immigrant populations.

Lack of information about all aspects of health care, including preventative treatments, treatment options, hospice, palliative care, and disease progression, is a prevalent problem within some cultures, particularly within immigrant communities where English is not the patient's native language. For example, nearly every interviewee said that hospice as a program/benefit was either unknown or not understood by a majority of their community.

### **Caregiving**

In many cultures the ideal situation is one in which the family provides all of the care for the patient. Having a stranger care for a family member—either in a hospital, nursing home or at home—may be considered offensive to some cultures.

Such non-medical services as homemaking, meals on wheels, or personal care attendants are generally considered desirable services, and patients and families would like to be informed of services that would be available to them. According to interviewees, some cultures may object to social work services due to a history with social work programs and frustrations from past experiences.

### **Financial issues**

Nearly all minority and immigrant communities face issues around lack of money or insurance. Many individuals from minority and immigrant communities are uninsured or poorly insured. This prevents patients from accessing many of the available end of life services. For example, the Indian Health Service, which insures and provides health care on Native American reservations, does not offer the same level of home care and hospice services that other health care systems provide (IHS, 2001).

Even when insurance is available, significant financial burdens may be imposed on family members for the care of their loved one, either in time constraints that prevent a caregiver from going to work, or in the financial cost of employing professional caregivers. Although these financial problems are not limited to minority and immigrant communities, their needs tend to be greater than those of the majority community due to their greater likelihood of living below the poverty line.

- Poverty rates in Minnesota by race/ethnicity (KFF, 2001):

9%	White
38%	Black
35%	Hispanic
5.5%	Asian
39%	Other

- Rate of non-elderly uninsured in Minnesota by race/ethnicity (KFF, 2001):

9%	White
20%	Black
23%	Hispanic
15%	Other

- Definition: Persons in poverty are defined as those who make less than 100% of the Federal Poverty Level (FPL). The federal poverty level for a family of three was \$13,290 in 1999 and \$14,630 for 2001.

## **RECOMMENDATIONS AND STRATEGIES**

In order to assure access to end of life services for minority and immigrant communities, providers and communities should partner to:

- Develop informational materials for minority and immigrant communities. This includes culturally-sensitive translated materials on such topics as advance care planning, hospice, grief and community services
- Training medical interpreters and health care professionals who service minority and immigrant communities on end of life care
- Develop, implement and evaluate a cultural assessment tool for health care providers. This tool would help those who provide care to understand patient and family values and beliefs, communication needs, caregiving needs, and decision-making style.

## **SUMMARY**

Improvement in care for minority and immigrant communities requires a multi-dimensional approach. Like the majority community, most prefer to remain at home, cared for by their families. For this to happen, health care providers need to be culturally sensitive when approaching end of life issues, patients and families need to have appropriate and understandable information, and the spiritual and cultural beliefs of each community need to be respected.



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# **END OF LIFE EDUCATION RECOMMENDATIONS**

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## END OF LIFE CARE EDUCATION

### INTRODUCTION

Education is essential to improving end of life care. The public needs to know the components of good care and where they can find the resources. Health professionals and health professional students need to be competent in providing that care. The Commission's discussion about education centered on strategies and recommendations that would increase both the demand for high-quality end of life services and the supply of those services.

Commission recommendations focus on three areas (listed below in no particular order):

#### *Area 1*

Educating the public through the organizations represented by the Commission, faith-based communities and other interested community organizations

#### *Area 2*

Educating health care professionals and health care organizations

#### *Area 3*

Educating undergraduate and graduate students in our colleges and universities

### COMMUNITY EDUCATION

Many people are unfamiliar with the services and resources available to those who are dying. Nor do they know what to expect from the systems that care for those who are dying. For example, in an April 1999 public opinion survey, the National Hospice and Palliative Care Organization (NHPCO) found that 80% of people did not know the meaning of the term "hospice," and only 2% mentioned that pain control was one of the services hospice offers. Additionally, 22% of people who lost a loved one in the past year due to a terminal illness used hospice services (NHPCO, 2001).

Forty-four percent of those polled did not know how hospice care is paid for. 90% of respondents did not know that Medicare is one of the funding mechanisms for hospice care. This knowledge deficit was consistent across age, income, education, and race populations (NHPCO, 2001).

While a variety of medical and community services are available to those with life-limiting illnesses, the system is fragmented and often very confusing. For example, the health care system offers nutrition counseling, but an entirely different system offers "meals on wheels." As the father of a dying child noted:

*"It's like we have two different worlds, the medical world and the social services world, and they don't talk to each other. I found some wonderful services for my daughter – but they were well hidden until I stumbled across them."*

Public discussion of issues surrounding end of life care continues to be problematic. Dying is still considered a taboo topic. A recent survey found that Baby Boomer parents are more comfortable talking with their children about safe sex than with terminally ill parents about their care wishes (NHF, 1999). However, changes are occurring in the willingness of people to look at this topic more openly. Commission discussions and subsequent roundtable discussions around the state indicate that more people are willing to talk about specific end of life planning issues including advance directives, funeral planning and hospice care. Interviews also indicate that faith communities around the state are increasingly interested in conducting discussion groups and informational sessions with their members. However, clergy and congregational leaders require more education about ways to present information in a sensitive and knowledgeable way.

## **HEALTH PROFESSIONAL EDUCATION**

While the public needs to understand end of life issues better, health professionals need to be able to provide the highest quality of care. Discussions with health care providers, both in the Commission meetings and in greater Minnesota, concluded that health care providers, including doctors, nurses, pharmacists, physical therapists, occupational therapists, and social workers, are not sufficiently knowledgeable about pain management, disease management, and end of life issues.

The ability to deal with death sensitively and without avoidance is a skill that can be learned. Health care professionals can be taught how to handle death and dying comfortably and sensitively (Curtis & Rubenfield, 2001). However, despite the capacity to learn how to deal with end of life situations, professionals encounter barriers to learning once they are on the job. For example, a focus-group study of social workers with extensive end of life experience identified cost, time away from work, and a biomedical focus of educational presentations as problems they faced when trying to increase their skills in end of life care (Christ & Sormanti, 1999).

Many dying patients require care that exceeds the skills of both generalists and specialist physicians (Von Gunten et al., 2000). According to research, certification in hospice and palliative care results in physicians who are highly qualified to provide palliative care, who can act as consultants to others, who can educate other specialists, and who can advocate for advancements and innovations in palliative medicine. Twenty-one of over 15,000 registered physicians and 159 of over 58,000 registered nurses in Minnesota are certified in hospice and palliative care (ABHPC, 2001 and HPCNA, 2001).

The Guiding Principles require a basic level of knowledge of end of life care issues. Education of health care professionals (medical doctors, nurses, pharmacists, physical therapists, occupational therapists, social workers) should include information on the following topics:

- Sensitive communication with end of life patients regarding advance care planning, disease progression, resources and treatment options
- Symptom management, including pain management and other physical symptoms
- Suffering assessment and intervention
- Grief and loss

## **EDUCATION FOR UNDERGRADUATE AND GRADUATE STUDENTS**

Because death is not solely a medical event, education on end of life issues should be addressed for all students. Although particular emphasis needs to be placed on those who will be caring for and interacting with people at the end of life, all students should have coursework available to them.

For students who will face end of life issues in their careers, education must move beyond the theoretical to the practical to prepare students for “bedside” care. Currently end of life training for students in the health professions is fragmented. For example:

- A study of four widely-used textbooks including *The Merck Manual* and *Harrison’s Textbook of Medicine* found little information that would help a physician care for a dying patient (Carron et al., 1999).
- A national study of nursing textbooks found that in a sample of fifty texts (45,683 pages), only 2% of the content was related to end of life care (Ferrill et al., 1999).
- Social work students are more likely than students in medicine, dentistry, nursing, and pharmacy to have an entire course devoted to end of life issues. However, these courses are generally electives, and fewer than 25% of students enroll (Kramer, 1998).
- A 1992 survey of sixty-one pharmacy schools, revealed that 62% offer no education on the subject of death and dying (Dickinson et al., 1992).
- Despite the high death rates for cardiovascular and other serious chronic illnesses, an innovative course offered to occupational therapy students on aging issues contained no information about end of life care (Colantonio et al., 2000).

## **RECOMMENDATIONS AND STRATEGIES**

Community organizations, educational institutions and health care organizations will promote and support education in the areas outlined by the Five Guiding Principles.

### **Community Organizations and the Public**

Educate organizations that have access to a network or membership base (e.g. faith-based and other organizations) on about such end of life topics as advance care planning, pain and symptom control, and hospice and palliative care

Identify, develop, and maintain a catalogue of materials on end of life topics

Distribute the Five Guiding Principles

### **Health Care Organizations/Practicing Professionals**

Support by Minnesota health care providers for the Five Guiding Principles

Encourage hospice and palliative care certification for physicians, nurses, and other health care professionals

### **Educational Institutions/Undergraduate and Graduate Education**

Include curriculum based on the Five Guiding Principles in academic programming

Fund further end of life care curriculum development and implementation through public and private sources

## **SUMMARY**

The education of our communities, health professionals, and students should be undertaken to ensure that high-quality care is delivered to patients at the end of life. The Commission on End of Life Care recommends that education should occur within member-based organizations, health care organizations, community organizations, and educational institutions. The Five Guiding Principles create the framework for all educational initiatives.

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**END OF LIFE CARE  
PUBLIC POLICY  
RECOMMENDATIONS**

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# END OF LIFE CARE PUBLIC POLICY

## RESIDENTIAL END OF LIFE SERVICES

### INTRODUCTION

Despite the fact that most people would prefer to receive their end of life care in their own homes, not everyone has the support system or resources to facilitate this desire. Improving the quality of end of life care entails addressing care wherever a person resides. The Commission has targeted two settings, assisted living and skilled nursing facilities, for recommendations because they are both part of the state's current infrastructure that service a significant number of people.

In addition, the Commission recognizes the added value to the community of the five licensed hospice residential facilities located in the state. Residential hospice programs are community-based facilities that provide hospice care in a home-like setting of up to twelve beds. Residential hospice care offers symptom management, comprehensive family support, spiritual care, bereavement follow-up, and volunteer services.

Charges for residential hospice services range from about \$200 to \$300 per day. Costs to the facility are typically even higher, which means the difference must be covered by fundraising. Medicare, Medicaid, and most private insurers in Minnesota will not cover this cost. Residential hospice programs are currently available only to a relatively small number of Minnesotans, and the number of beds available is limited by the number of people who can afford this care.

Medicare and Medicaid funds for residential care at the end of life may only be spent in certified nursing facilities. Public funds to support housing for the elderly and disabled is also available through Federal and local subsidized housing programs. Residential care to those who are near the end of life is provided (both subsidized and at market rate) in apartment buildings and other congregate housing for seniors, also known as assisted living.

The Commission seeks to improve residential care at the end of life for all Minnesotans, including those who cannot afford residential hospice. As described above, the alternative settings are assisted living programs and skilled nursing facilities.

### **Assisted Living**

In Minnesota, "assisted living" or "housing with services" is more of a service concept than an actual place. "Housing with services" encompasses a variety of senior residential settings that offer certain types of supportive services or health-related services for a fee (SAIL Project, 1999). More and more of our aging population are looking at assisted living as an alternative to nursing home residence. The demand and use of assisted living services has increased dramatically in the past five years. In 1997 Minnesota had 13,000 units. In 1999 the number had grown to 27,000. Those who work within assisted living recognize it as a rapidly-growing and evolving housing and service industry.

Minnesota has 621 registered “housing with services” facilities. Generally, residents live in their own apartments but have services such as meals, homemaking, laundry, and personal assistance available to them. Services and cost vary from facility to facility.

Room and board costs for assisted living are generally paid privately by the resident (just as rent, mortgage and food would be paid privately for people living in their own homes). Residents with limited funds can qualify for some public financial assistance under the elderly waiver or alternative care grant.

Commission discussions as well as interviews with hospice providers, assisted living care providers, and consumers reveal the need to integrate end of life care within this rapidly-growing and evolving industry. As a nurse who works in an assisted living facility stated: “We are seeing frailer residents with more and more complex needs.”

Residents in assisted living facilities are often there because of a combination of declining health and the absence of an informal caregiver. The desire to honor residents’ wishes to stay in their apartments and the increasing complexity of care can be problematic. Barriers to good care include late identification of patients who could benefit from hospice services, confusion over payment for care when hospice is involved, and fragmented communication between hospice and assisted living health care providers.

### **Skilled Nursing Facilities**

Over 38% of those who die in Minnesota die in a skilled nursing facility. In 1999, 45% of discharges from skilled nursing facilities were due to death ([www.health.state.mn.us](http://www.health.state.mn.us), 2000). While many people who are admitted die, recovery and restoration are the focuses in skilled nursing facilities.

Skilled nursing facility costs are paid either by Medicare, Medicaid or the individual. However, Medicare coverage is limited. (For more information on the qualifying conditions for Medicare coverage of skilled nursing facility care see the Medicare web site at <http://www.medicare.gov> or call (800) M-E-D-I-C-A-R-E. In Minnesota, call (800) 333-2433 to speak to a local health insurance counselor.)

Skilled nursing facilities often do not have adequate funding to provide comprehensive end of life care. These facilities will often work with hospice programs to enhance end of life care for their patients. Recent research has shown that patients receiving hospice services within a skilled nursing facility receive better pain management than those receiving standard care. (Zerzan, Stearns, & Hanson, 2000).

In addition, workforce issues result in barriers to excellent end of life care. Because many skilled nursing facilities have large staff turnover, they are unable to maintain a workforce that is educated and skilled in caring for those who are dying.

### **Rural Access to Assisted Living and Skilled Nursing Care**

Rural areas face particularly challenging issues in terms of residential end of life care. A combination of a limited skilled workforce, a dwindling number of informal caregivers, and a limited number of assisted living and skilled nursing facilities magnify the problem.

## **RECOMMENDATIONS AND STRATEGIES**

Public and private policy makers will promote and implement improvements in the area of residential end of life services:

- Pursue funding from new or reallocated resources to study removal of reimbursement and other barriers to hospice and end of life services within assisted living and skilled nursing facilities. Funding studies would:
  - Address interdisciplinary care needs of patients and residents
  - Address staff education needs regarding the Five Guiding Principles including advance care planning, pain and symptom management and grief
  
- Promote hospice and long-term care partnerships to explore alternative and innovative residential programs for end of life care. This might include:
  - Partnerships to create hospice beds in skilled nursing facilities
  - Partnerships with hospice and the community to provide volunteers for patients and residents
  - Partnerships to provide training in skills needed to implement the Five Guiding Principles

## **SUMMARY**

High quality end of life services should be available to all Minnesotans no matter where they reside. The Commission's recommendations support exploring creative ways to ensure this type of care within our existing system.

## END OF LIFE CARE PUBLIC POLICY

### OUT-OF-HOSPITAL END OF LIFE CARE BY EMERGENCY MEDICAL SERVICES (EMS)

#### INTRODUCTION

Many people with terminal illnesses who live at home, in residential settings, or in skilled nursing facilities do not wish to have aggressive treatments such as cardio-pulmonary resuscitation (CPR) at the end of life. While Minnesota has an established system to respect these wishes through a physician generated “Do not resuscitate” order (DNR), procedures and policies regarding the DNR order vary throughout the state. Providers, families and physicians are unclear on how to implement and use the DNR orders. Additionally, the state does not have a system that allows EMS personnel to provide comfort measures in place of aggressive treatment.

The confusion over resuscitation of a terminally ill patient can be frustrating for paramedics and emergency medical providers, and devastating for families. EMS personnel are charged with a “duty to treat” with CPR that can be in conflict with the wishes of the patient or the family. As one paramedic said, “One of the hardest things for me to do is begin CPR on a frail, obviously terminal patient knowing I will break ribs and add to the suffering.”

Currently, Minnesota has nearly 300 different ambulance services, each with its own protocols. Confusing issues over the use of DNR orders include:

- ***Variety of forms***  
Use of different forms varies from area to area
- ***Rules for renewal***  
There is variation of the rules about how often DNR orders need to be renewed
- ***Policies and procedures in various settings***  
Policies within residential care, such as assisted living facilities, that automatically require resuscitation, even against a patient’s wishes or a physician’s order will vary from facility to facility
- ***Availability of orders for EMS personnel on arrival***  
DNR orders that are not readily available when an ambulance is called can cause multiple problems for EMS personnel when they arrive

Both health care providers and the public often confuse DNR orders and health care directives. A DNR order is a *treatment order* generated by a physician. A health care directive is a patient’s statement of preference for treatment. In an emergency transportation situation, transport personnel are not obligated to read or honor a health care directive. However, they are obligated to follow a DNR order from a physician.

## **RECOMMENDATIONS AND STRATEGIES**

The Commission recommends that the health care systems, emergency medical systems, and the community:

- Develop a standard and simplified vocabulary around policies and portability for physician orders regarding cardio-pulmonary resuscitation (CPR) and comfort care in order to enhance understanding and implementation by EMS personnel who respond to 911 calls at private residences and nursing homes
- Educate the public and health professionals regarding the use of out-of-hospital CPR and comfort care orders

## **SUMMARY**

Minnesota has a system for out-of-hospital DNR orders. The implementation of this system varies and is a source of confusion for patients, families, and providers. The Commission recommends the establishment of standard and simplified language concerning the implementation of DNR and comfort care orders and subsequent provider and public education about this.

# END OF LIFE CARE PUBLIC POLICY

## END OF LIFE CARE DECISION-MAKING FOR PERSONS WITHOUT DESIGNATED DECISION-MAKERS: ADULT ORPHANS

### INTRODUCTION

The population known as “adult orphans” includes adults who lack a family or a designated decision-maker. “Unbefriended adults” represents a sub-category of adult orphans. These are people who are often homeless or who live in marginal settings due to long histories of chemical abuse, mental illness, or mental incapacity. When people within these populations lose decision-making ability, they often have no one who can make end of life treatment decisions for them. Patients in this population can be denied comfort-oriented care because the care or treatment requires informed consent.

### POPULATION

Little data exists on the number of people who fall into the adult orphan category. In a 1989 study of nursing home residents, 45% of the next of kin listed in the charts could not be reached for participation in major decisions regarding resuscitation status (Fader et al., 1989). In Minnesota, social services staff from Volunteers of America estimate that they handle approximately 250 calls per year regarding end of life decisions about people who have impaired decision-making capacity and who have no legally designated decision-maker. The Alzheimer’s Association of Minnesota agrees that the problem is very real and that the numbers of adult orphans reaching the end of life are growing.

A variety of diseases are likely to decrease a person’s capacity for making decisions at some point, especially at the end of life. Patients with such illnesses as dementia, Alzheimer’s disease, brain injuries, intellectual disabilities, mental illness, chemical dependency, the frail elderly, stroke victims, and patients in persistent vegetative states are particularly at risk. In one study of long-term care residents, 47% lacked all decision-making capacity and another 26% retained only partial capacity (Miller & Cugliari, 1990).

### SUBSTITUTED JUDGEMENT AND BEST INTEREST

Two ethical standards of decision-making by proxy provide a framework for considering how to best intervene with the adult orphan population.

#### **Substituted Judgement**

In the absence of a written directive, a surrogate can come to the same decision the patient would if he or she had the decision-making capacity. Substituted judgement involves knowing the patient and understanding care wishes and goals at the end of life.

#### **Best Interest**

With this principle, the surrogate need not have knowledge of treatment preferences. Instead, he or she applies a general understanding of societal values in order to make treatment decisions.

Ideally, the surrogate decision-maker would use substituted judgement as the basis for treatment choices. The best interest principle can be problematic because the surrogate's own background and values may effect his or her decision.

## **CONSERVATORSHIP IN MINNESOTA**

Medical decisions for patients at the end of life often have to be made quickly. Minnesota's current process for conservatorship is in many cases too cumbersome and time-consuming for end of life care decisions.

The current process for conservatorship takes approximately six to eight weeks. Funding is available to pay for a conservator's time once he or she is appointed, but the legal fees, the conservatee's legal fees, and court costs, which amount to approximately \$1,950 are the patient's responsibility. If the petition is contested the fees are much higher. An emergency conservatorship process, with a one to three-day turnaround is available in cases of life-or-death, but this process is primarily reserved for life-saving interventions.

## **CHALLENGES**

**Treatment decisions that require consent.** Palliative treatment decisions are usually made with the input of the patient or family. In some cases, these treatment decisions require informed consent. For example, a procedure to implant a pain control device in the body requires consent by the patient. In the case of the adult orphan who lacks a legal decision-maker, it may be difficult to change the nature of care as patient needs change.

**Hospice care.** Enrollment into a hospice program also requires informed consent on the part of the patient or the legal decision-maker. Adult orphans might not be able to receive hospice services because of the lack of a decision-maker and the time it takes to designate one through the legal system.

**Lack of research.** Little research exists concerning the population of adult orphans at the end of life. Understandably, this population is difficult to identify and locate. Very little information describes where these patients live, where they are cared for, and what the most favorable course of action should be regarding their health care decisions.

## **RECOMMENDATIONS AND STRATEGIES**

For adult orphans who lack decision making capacity, public and private policy makers should promote and implement improvements in end of life care to:

- Develop procedures within health care systems (hospitals, clinics, long term care etc.) to identify those people who do not have responsible family members or other resources to make surrogate health care decisions.
- Develop a system to assist adult orphans in identifying a health care agent (surrogate) or executing a health care directive.
- Explore options for an expedited decision making process that recognizes the need to make emergency comfort care or palliative care treatment decisions.

## **SUMMARY**

The population of people defined as adult orphans are particularly at risk at the end of life because they often lack decision-making capacity and a surrogate to make decisions for them. Recommendations include earlier identification of those at risk and earlier intervention with them to identify end of life health care wishes and goals. In addition, the Commission recognizes the need for a process to assure that adult orphans will receive appropriate and timely emergency comfort care and palliative care treatments.

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# **LOOKING AHEAD**

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## NEXT STEPS

Great things are not done by impulse, but by  
a series of small things brought together.  
~ *Vincent Van Gogh*

The work of improving care at the end of life is only at the beginning stages. The Commission has identified issues and made recommendations and strategies. Minnesota now has a framework on which to build a better kind of care. However, the work of the Commission will result in change only if both public and private sector leaders endorse the recommendations and commit to putting them into action within their own organizations.

Each organization concerned with improving care needs to study the recommendations and decide on those that can be incorporated into their overall strategic plan. This could mean that the Minnesota Department of Health integrates the Five Guiding Principles into its survey process to assure that patients and families receive adequate teaching, symptom management, or bereavement follow-up. This could mean that home care agencies identify patients who have a life-limiting illness and begin to discuss advance care planning. This could mean that social service organizations who provide information and referral to aging populations are familiar with the end of life resources in their area.

Next steps also involve engaging the public in understanding that they have choices and options for care at the end of life. This needs to happen on a personal and family level as well as a community level. For all who read this report and ask, “What can we do?” remember the words of Mahatma Gandhi: “We must become the change we want to see.”



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## WEB DIRECTORY

### COMMISSION MEMBERS

#### **AARP**

<http://www.aarp.org/statepages/mn/html>

#### **Center for Cross-Cultural Health**

<http://www.crosshealth.com>

#### **Emergency Medical Services Regulatory Board**

<http://www.emsrb.state.mn.us>

#### **Minnesota Board on Aging**

<http://www.mnaging.org>

#### **Minnesota Citizens Concerned for Life**

<http://www.mccl.org>

#### **Minnesota Department of Health**

<http://www.health.state.mn.us>

#### **Minnesota Health and Housing Alliance**

<http://www.mhha.com>

#### **Minnesota Hospice Organization**

<http://www.mnhospice.org>

#### **Minnesota House of Representatives**

<http://www.house.leg.state.mn.us>

#### **Minnesota State Bar Association**

<http://www.mnbar.org>

#### **University of Minnesota Academic Health Center**

<http://www.ahc.umn.edu>

#### **Care Providers of Minnesota**

<http://www.careproviders.org>

#### **Center for Rural Health**

<http://www.ruralcenter.org/mcrh>

#### **Jay Phillips Center for Jewish-Christian Learning**

<http://www.stthomas.edu/jpc>

#### **Minnesota Center for Health Care Ethics**

<http://paradox.stkate.edu/mnethx>

#### **Minnesota Council of Health Plans**

<http://www.mnhealthplans.org>

#### **Minnesota Department of Human Services**

<http://www.dhs.state.mn.us>

#### **Minnesota HomeCare Association**

<http://www.mnhomecare.org>

#### **Minnesota Hospital and Healthcare Partnership**

<http://www.mhhp.com>

#### **Minnesota Medical Association**

<http://www.mnmed.org>

#### **Minnesota State Council on Disability**

<http://www.disability.state.mn.us>

#### **University of Minnesota Center for Bioethics**

<http://www.bioethics.umn.edu>

### END OF LIFE CARE RESOURCES

#### **American Academy of Hospice and Palliative Medicine**

<http://www.aahpm.org>

**American Association of Colleges of Nursing: End-of-Life Nursing Education Consortium (ELNEC) Project**

<http://www.aacn.nche.edu/ELNEC/>

Providing resources and curriculum to educate nurses in end of life care.

**Americans for Better Care of the Dying**

<http://www.abcd-caring.com>

Dedicated to ensuring that all Americans can count on good end-of-life care, ABCD focuses its efforts on improved pain management, financial reimbursement systems, continuity of care, support for family caregivers, public policy and other fundamental reforms.

**Approaching Death: Improving Care at the End of Life**

<http://www.nap.edu/readingroom/books/approaching>

**Barbara Ziegler Palliative Care Education Program of Memorial Sloan-Kettering Cancer Center**

<http://www.mskcc.org>

**Caring Conversations: Making Your Wishes Known for End-of-Life Care**

(A Program offered by the Midwest Bioethics Center)

<http://www.midbio.org>

Program components include a workbook on end-of-life issues, a resource booklet of consumer education about healthcare and end-of-life decisions, an adult study group guide and video, and other resources.

**Dying Well**

<http://www.dyingwell.org>

Provides written resources and referrals to organizations, web sites, and books to empower persons with life-threatening illness and their families to live fully.

**End of Life Physician Education Resource Network**

<http://www.eperc.mcw.edu>

EPERC is a program sponsored by Medical College of Wisconsin for physicians and physician educators regarding end of life issues. The site provides peer-reviewed training materials and links to other similar sites.

**Ethical Wills**

<http://www.ethicalwill.com>

**Growth House, Inc**

<http://www.growthhouse.org>

Provides comprehensive resources about life-threatening and terminal illnesses, hospice and home care, pain management, palliative care, death and bereavement.

**Hospice Foundation of America**

<http://www.hospicefoundation.org>

Provides access to videotapes, books, newsletters and brochures about end-of-life care and grief issues.

**The International Work Group on Death, Dying, and Bereavement**

<http://users.imag.net/~lon.death/iwg/iwg.html>

**Last Acts Campaign**

<http://www.lastacts.org>

Provides information on end-of-life care and new legislation. Also offers on-line discussion groups and many helpful links to related sites.

**MedicAlert Foundation**

<http://www.medicalert.com>

Provides DNR emblems and advance directive repository services.

**Medical Directive Worksheets**

<http://www.medicaldirective.org>

End-of-life care worksheets are available to order that can help people determine the treatment they want if they become gravely ill and unable to speak for themselves.

**NPR Exploring Death in America**

<http://www.npr.org>

**National Hospice and Palliative Care Organization**

<http://www.nhpc.org>

NHPCO is a professional organization that provides information on hospice programs available in your area, and general information about hospice services.

**On Our Own Terms: Moyers on Dying Thirteen/WNET New York**

<http://www.pbs.org/onourown/terms>

Provides information and resources about decision-making and care at the end of life based on the Public Broadcasting Service Bill Moyers series, On Our Own Terms.

**Partnership for Caring, Inc. (Previously Choices in Dying)**

<http://www.partnershipforcaring.org>

Provides a 24-hour hotline offering up to date information about advance directive laws for individual states and general information about end-of-life issues and decision making. Also provides individual states' legally recognized advance directive document.

**Project on Death in America: Soros Foundation**

<http://www.soros.org/death.html>

**Promoting Excellence in End-of-life Care**

<http://www.promotingexcellence.org>

Located at the University of Montana, this RWJF funded program sponsors clinician and researcher peer workgroups and directs long-term end of life care development projects. These projects focus on special populations of patients, particularly those with terminal diseases and illnesses. It challenges clinical settings and reaches out to underserved Native American community.

### **Toolkit of Instruments to Measure End of Life Care**

<http://www.toolkit.htm>

### **U.S. Living Will Registry**

<http://www.livingwillregistry.com>

A national free service that will register and store an advance directive on a computer database that can then be faxed directly to hospitals if needed.

Assistance for CareGivers and In-Home Services RESOURCES

### **Caregivers Survival Resources**

<http://www.caregiver911.com>

Provides information about disease-related support groups and general resources for caregivers.

### **Children of Aging Parents (CAPS) / Careguide**

<http://www.careguide.net>

CAPS has a national mission to provide the 22.4 million family caregivers with reliable information and referrals, a network of support groups, and publications and programs that promote public awareness of the value and the needs of caregivers. CAPS provides phone numbers and names of nursing homes, retirement communities, elderlaw attorneys, day care centers, medical in-home services, respite care, assisted living centers, state and county agencies and more. CAPS also writes, collects, and disseminates fact sheets on various topics.

### **Meals-on-Wheels Association of America**

<http://www.projectmeal.org>

Provides information about the Meals-on-Wheels program in your area.

### **National Association for Home Care**

<http://www.nahc.org>

### **National Federation of Interfaith Volunteer Caregivers**

<http://www.nfivc.org>

Will find a volunteer to help with supportive services to the frail elderly and their caregivers.

### **The Well Spouse Foundation**

<http://www.wellspouse.org>

The Well Spouse Foundation was formed to give emotional support, raise consciousness about, and advocate for the spouses and children of the chronically ill and/or disabled.

## **ELDER CARE RESOURCES**

### **Aging with Dignity**

<http://www.agingwithdignity.org>

Provides the health care directive document “Five Wishes,” which is legal in 36 states

**American Society on Aging (ASA)**

<http://www.asaging.org>

ASA is a professional society that provides educational programs, publications and information, and training resources.

**Eldercare Locator**

<http://www.aoa.dhhs.gov/elderpage/locator.html>

A nationwide directory assistance service designed to help older persons and caregivers locate local support services for aging Americans, including information about how to contact your State Agency on Aging. It is a public service of the Administration on Aging and the U.S. Department of Health and Human Services and is administered by the National Association of Area Agencies on Aging and the National Association of State Units on Aging.

**National Aging Information Center**

<http://www.aoa.dhhs.gov>

**National Council on Aging**

<http://www.ncoa.org>

**National Institute on Aging**

<http://www.nih.gov/nia/>

The National Institute on Aging (NIA), one of the 25 institutes and centers of the National Institutes of Health, leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life.

**Resource Directory for Older People**

<http://www.aoa.dhhs.gov/aoa/dir/intro.html>

Provides an online directory compiled by the National Institute on Aging (NIA) and the Administration on Aging (AoA) or the elderly, caregivers, health and legal professionals, social service providers, and others.

**Senior Scape Elderlinks**

<http://www.seniorscape.com>

Provides a regularly updated list of elder care resources. The website is a cooperative effort of the National Institute on Aging (NIA) and the Administration on Aging (AoA).

**GRIEF AND LOSS RESOURCES**

**Association for Death Education and Counseling**

<http://www.adec.org>

A Professional Organization that provides educational tools to increase awareness and acceptance of the grieving process.

**Beyond Indigo (formerly Death and Dying)**

<http://www.death-dying.com>

This site offers grief support, message boards, memorial postings, story archives, and a wide array of information on how to cope with grief.

### **Grief and Loss Resource Centre**

<http://www.rockies.net/~spirit/grief/grief.html>

This site provides a comprehensive list of links to bereavement related web pages as well as support and advice.

### **National Cancer Institute: Grief, Loss and Bereavement.**

<http://www.graylab.ac.uk/cancernet/506750.html>

A resource provided by the National Cancer Institute specifically for cancer related emotional hardships.

## **CROSS-CULTURAL HEALTH RESOURCES**

### **Agape/Community Care**

[http://www.baylor.edu/~Charles\\_Kemp/agape.htm](http://www.baylor.edu/~Charles_Kemp/agape.htm)

A Baylor University sponsored initiative providing cultural resources for the health care community. Links to information about Asian and Latino health practices, refugee health issues are available through this site.

### **Community and Cross-Cultural Health**

[http://nurseweb.ucsf.edu/www/cch\\_main.htm](http://nurseweb.ucsf.edu/www/cch_main.htm)

A specialty program at the School of Nursing of the University of California San Francisco focusing on the advancement of healthcare for vulnerable communities.

### **Cross Cultural Healthcare program**

<http://www.xculture.org/>

In attempts to bridge the gap between health care providers, and increasing ethnic and linguistic diversity in the community CCHCP offers a broad range of services. Available on the Web site are books and information resources, training programs, research initiatives and translation/interpretation services.

### **Diversity RX**

<http://www.diversityrx.org>

This organization offers medical interpretation resources, legal advice and policy directives. Through programs aimed at reducing the impact of language barriers, Diversity RX works toward extending quality healthcare across diverse minority, immigrant and ethnic communities.

## **PEDIATRIC RESOURCES**

### **The American Academy of Pediatrics**

<http://www.aap.org>

The AAP website has news and information on most childhood health issues from immunization to cancer treatment.

**The American Cancer Society**

<http://www.cancer.org>

The ACS has a wonderful Children's Resource Center that has very helpful information on cancer in children.

**The Children's Hospice International**

<http://www.chionline.org>

CHI is a marvelous website. They have a child-friendly interactive section as well as a part dedicated to publications and documentation for parents and health care providers.

**Pain Management for Children with Cancer**

<http://www.childcancerpain.org>

**PedsChat**

<http://www.pedschat.org>

The International Pediatric Chat website allows professionals from all over the globe to come together to discuss problems, issues and concerns about pediatric health care.

**Starbright World**

<http://www.starbright.org>

The website for the Starbright World is an interactive website for children and teens who are facing serious illness. It includes a multi-media educational tool to help children understand their illnesses.

**JOURNALS**

**American Journal of Nursing**

<http://www.nursingworld.com>

**British Medical Journal**

<http://www.bmj.com>

**European Journal of Cancer**

<http://www.eurjcancerprev.com>

**JAMA**

<http://jama.ama-assn.org>

**Journal of National Cancer Institute**

<http://jnci.oupjournals.org>

**The Lancet**

<http://www.thelancet.com>

**Progress in Palliative Care**

<http://www.leeds.ac.uk/lmi/ppc/ppcmain.htm>

**Annals of Internal Medicine**

<http://www.annals.org>

**Cancer Research, Oncology & Pathology**

<http://www.wiley.com>

**European Journal of Palliative Care**

<http://www.ejpc.co.uk>

**Journal of Clinical Oncology**

<http://www.jco.org>

**Journal of Palliative Medicine**

<http://www.catchword.com>

**New England Journal of Medicine**

<http://www.nejm.org>

**U.S. National Library of Medicine**

<http://www4.ncbi.nlm.nih.gov/PubMed>

## GLOSSARY OF END OF LIFE TERMS

### **Advance Directive**

A legal document in which people state their wishes regarding medical treatment and preferences in case they are incapacitated. Advance directives include living wills, health care directives, and medical power of attorney. In Minnesota an advance directive is referred to as a **health care directive**. The person appointed to make decisions in case of incapacitation is called the **health care agent**.

### **Advance Care Planning**

A thoughtful family-based discussion about care wishes and goals as someone faces end of life decision-making. The goals of advance care planning are three-fold:

- To elicit clear understanding of the kind of care a person facing a life-threatening or life-limiting illness would want
- To determine who would speak for that person if he were unable to speak for himself (health care agent)
- To complete a written health care directive

### **Cardiopulmonary Resuscitation (CPR)**

Refers to a group of treatments used when a person's heart stops beating or a person stops breathing. It can include any of the following: mouth-to-mouth breathing, chest compressions (pressing on the chest to push blood through the heart), electric shock, (paddles), and drugs used to stimulate the heart.

### **Comfort Care**

Care that relieves pain and suffering and controls debilitating symptoms but does not prevent dying. This includes:

- Administration of medications or other treatments such as radiation to relieve pain
- Administration of medications for anxiety, constipation, breathing difficulty and other symptoms
- Provision of personal care such as bathing and turning
- Provision of emotional and spiritual support to the dying person, family and friends
- Administration of other treatments that enhance comfort

### **Decision-Making Capacity**

The ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.

### **Do Not Intubate (DNI)**

A physician's order **not** to pass a tube into a patient's windpipe to facilitate breathing. Intubation includes use of an artificial breathing machine called a ventilator.

### **Do Not Resuscitate (DNR)**

Also called "no code," a DNR is a physician's order to **not** attempt to restart a failed heartbeat or to apply cardiopulmonary resuscitation (CPR) to restore normal breathing.

### **Health Care Directive**

See advance directive.

### **Health Care Agent/Proxy**

The person designated in a health care directive to make decisions for a patient if the patient lacks decision-making capacity.

### **Hospice**

A philosophy of care for people who are dying that emphasizes comfort over cure. Hospice care is available in a wide variety of settings including the home, hospitals, nursing homes, and residential hospices. Hospice care is provided by an interdisciplinary team of health care professionals who:

- Attend to the physical, emotional and spiritual needs of the patient and family
- Have expertise in pain and symptom management
- Follow up with grief support services for the family

### **Hospice Medicare Benefit**

A special benefit under Medicare Part A that covers hospice services. Criteria for hospice admission include:

- A terminal illness with a prognosis of six months or less as certified by a physician
- Patient consent to pursue a “hospice philosophy of care” that includes a focus on comfort rather than either cure or prolonging life

The hospice Medicare benefit includes:

- Interdisciplinary team support from nurses, social workers, chaplains, volunteers, home health aides and therapists
- Coverage for all prescriptions and treatments related to the terminal illness. In patient respite care
- Medical equipment to maintain patient comfort such as oxygen or a hospital bed
- 24 hour hospice on-call service
- Bereavement follow-up for the family

### **Living Will**

See advance directive.

### **Medical Power of Attorney**

Another name for a **health care agent**. A medical power of attorney has authority to make medical decisions. This is **not** the same as a power of attorney for property or financial matters.

### **Palliative Care**

Care focused on relieving symptoms rather than curing a disease. Like hospice care, it addresses the physical, emotional and spiritual needs of a patient and family.

### **Terminal Illness**

An illness or condition that is incurable and irreversible. When a person is diagnosed as terminally ill, death is expected in a relatively short period of time.

### **Ventilator**

A machine that helps a patient breathe. Sometimes it is used temporarily until a person can breathe without assistance and other times it is a permanent breathing aide.



## APPENDIX 1

### THE COMMISSION ON END OF LIFE CARE ORGANIZATIONS AND MEMBERS

#### **AARP**

*Lillian Eid*

AARP is a nonprofit association dedicated to shaping and enriching the experience of aging for their members and for all Americans.

#### **Care Providers of Minnesota**

*Helen Framptom (Margaret Owen and Pam Guyer also served)*

Care Providers is a partner organization for long-term care providers, designed to support them in providing the highest quality care to their customers.

#### **Center for Cross Cultural Health**

*Okokon Udo*

The Center for Cross-Cultural Health is committed to integrating the role of culture into health.

#### **Déva House**

*Angie Smith Lillehei, RN, MPH*

The mission of Déva House is to support children with life-threatening illness and their families by conducting programs of care, support, education, and research.

#### **Insurance Consultant**

*Theresa McManaman*

Medica Health Insurance will provide content and quality improvement expertise.

#### **Jay Phillips Center for Jewish-Christian Learning**

*Rabbi Barry Cytron*

The Jay Phillips Center for Jewish-Christian Learning, a partnership between two educational institutions, promotes interfaith understanding and cooperation.

#### **Minnesota Board on Aging**

*Jeanette Metz*

The Minnesota Board on Aging is a conduit for seniors and their families to access a variety of services.

#### **Minnesota Center for Health Care Ethics**

*Karen Gervais, PhD*

The Minnesota Center for Health Care Ethics promotes ethically-informed health care decision-making through education, decision making assistance, and scholarly contributions to the field of health care ethics and policy.

**Minnesota Center for Rural Health**

*Sally Buck*

The Minnesota Center for Rural Health ensures access to health care for rural and underserved citizens, recruits health care personnel to serve in rural communities, and assists and supports rural communities with a variety of strategies and projects.

**Minnesota Citizens Concerned for Life**

*Catherine Blaeser*

Minnesota Citizens Concerned for Life is an advocacy group that protects the human right to life through member education and by keeping the public and lawmakers informed on critical life issues.

**Minnesota Coalition for Death Education and Support**

*Ben Wolfe, Med LICSW*

The Minnesota Coalition for Death Education and Support promotes and provides education, networking opportunities and support to persons involved with care for those confronting death and their families, friends and bereaved.

**Minnesota Council of Health Plans**

*MaryAnne Stump, RN, MS*

The Minnesota Council of Health Plans is an association of nonprofit, Minnesota-based health plan companies who are dedicated to information dissemination and to improving health care access, quality, and affordability.

**Minnesota Department of Health**

*Commissioner Jan Malcolm* will serve as co-chair on the Commission on End of Life Care while representing the Minnesota Department of Health.

**Minnesota Department of Human Services**

*Kathleen Cota*

The Minnesota Department of Human Services provides health care, economic assistance, and social services for people who do not have the resources to meet their basic needs.

**Minnesota Emergency Medical Services Regulatory Board**

*Mary Hedges (David Huisenga also served)*

The Minnesota Emergency Medical Services Regulatory Board provides leadership which optimizes the quality of emergency medical care for the people of Minnesota.

**Minnesota Health and Housing Alliance**

*Andrew Tumberg*

The Minnesota Health & Housing Alliance is comprised of members who provide a complete continuum of services for older adults. The Alliance is dedicated to promoting interests through leadership, advocacy, networking and education and to helping people live as independently as possible by providing a variety of services.

### **Minnesota Home Care Association**

*Steve Lund*

The Minnesota Home Care Association consists of a diverse consortium of providers who work to promote quality care in a variety of living environments and to facilitate community awareness.

### **Minnesota Hospice Organization**

*Elinor Hands*

The Minnesota Hospice Organization's mission is to promote quality care for people who are dying and for their families.

### **Minnesota Hospital and Healthcare Partnership**

*Elizabeth Woll*

The Minnesota Hospital and Healthcare Partnership is a trade organization representing Minnesota's hospitals and health systems.

### **Minnesota House of Representatives**

*Representative Michelle Rifenberg* represented the Minnesota House of Representatives on the Commission on End of Life Care.

### **Minnesota Medical Association**

*Mark Leenay, MD*

The Minnesota Medical Association is dedicated to developing and maintaining an environment in which physicians are able to deliver appropriate patient care and promote public health.

### **Minnesota Partnership to Improve End of Life Care**

*Barry Baines MD Commission Co-chair*

*Edward Ratner, MD, Principal Investigator*

The Minnesota Partnership to Improve End of Life Care is a partnership of health care providers dedicated to raising the standards of end of life care in Minnesota.

### **Minnesota State Bar Association**

*John Diehl*

The Minnesota State Bar Association works to aid the courts in administering justice, conducts programs of continuing legal education and applies the experience and knowledge of the legal profession to the public good.

### **Minnesota State Council on Disability**

*Don Westergard*

The Minnesota State Council on Disability works to expand opportunities for all persons with disabilities and to advocate for policies and programs which will promote their independence and participation in society.

### **Pediatric Consultant**

*Joanne Hilden, MD* provided content information on pediatric end of life care.

**University of Minnesota Academic Health Center**

*Paul Quie MD*

The Academic Health Center at the University of Minnesota strives to be a leader in the ethical, innovative and efficient discovery and dissemination of knowledge to enhance the health and well-being of Minnesotans.

**University of Minnesota Center for Bioethics**

*Dianne Bartels, RN PhD*

The University of Minnesota Center for Bioethics' mission is to advance and disseminate knowledge concerning ethical issues and the life sciences.

**Staff and resource support for the Commission on End of Life Care**

Minnesota Partnership to Improve End of Life Care staff

*Linda Norlander, RN, MS Project Director*

*Brenda Paul, Communications Coordinator*

*Jackie Bruno, Education Specialist*

Minnesota Department of Health

*Buddy Ferguson, Policy and Communications Information Officer*

*Kay Markling, Facility and Provider Compliance*

## APPENDIX 2

### OTHER ISSUES

The following is a list of issues discussed in Commission meetings but not brought forward for recommendation. While all issues identified were considered important, these were not acted upon for a variety of reasons. Some were too large for the scope of the Commission, some were out of the sphere of control of the Commission, some did not have enough support to be brought forward, and some were incorporated into other Commission recommendations.

#### **Cost and Reimbursement for End of Life Care**

The Commission chose not to pursue these issues because of the complexity of the private/public reimbursement system and the link to federal rules and regulations outside the scope of the Commission's charge.

- Reimbursement for palliative care/advance care planning consultations by interdisciplinary team members (nurse, social worker, chaplain)
- Uniform definitions of end of life coverage from third-party payers
- Establishment of a different Medicaid asset limit for enrollment in programs focused on palliative or hospice care

#### **Standards of Care**

The Commission discussed at length the issue of creating clinical standards for end of life care. Since the Commission is not a regulatory body and would not have the ability to measure or enforce standards, the Five Guiding Principles were created as a framework for care for organizations involved in creating standards. Issues identified in this area included:

- Recognition of pain as a fifth vital sign
- Health care provider licensure requirements that include competency in end of life care
- Development of symptom algorithms for such clinical areas as pain
- Development of emergency medical system protocols for provision of comfort care for dying patients

#### **Knowledge, awareness, attitudes, and education**

Many of the issues raised regarding public knowledge and attitudes have been more broadly addressed in the education recommendations. Concerns raised included:

- Creation of a patient bill of rights for end of life care
- Targeted education for long-term care
- Education on end of life care for grades K-12
- Work toward changing public attitude about dying and death
- Education for consumers on asset management

#### **Issues requiring changes on the federal level**

The following were identified as barriers to high-quality end of life care that would require changes on a federal level:

- Six month prognosis requirement to enroll in the hospice Medicare benefit
- Need for physician involvement in the plan of care for hospice enrollment

- Reimbursement “red tape” for hospice and skilled nursing facilities when a patient receiving room and board assistance through Medicaid enrolls in hospice

**Other issues**

The following issues were identified but not acted upon for a variety of reasons:

- Depleted health care workforce—deemed too broad for the scope of the Commission
- Bedsores—addressed in a broader sense under the Five Guiding Principles and Education
- Use of the emergency medical system to manage pain—lack of demonstrated need and too clinically complex for the scope of the Commission
- Restricted access to opioids in some areas and neighborhoods—lack of demonstrated need
- Inability of patients to enroll in hospice because of expensive treatments—deferred to Minnesota Hospice Organization
- Lack of funding for the Minnesota Department of Health to conduct hospice regulatory surveys—to be handled within the Department of Health
- Resistance by assisted living programs to enroll patients in hospice programs—lack of confirmation that this is a problem

### APPENDIX 3

#### ACKNOWLEDGEMENTS: ASSISTANCE AND INPUT

The following people provided assistance with background information, public policy issues, and other types of additional support:

**Bob Anderson**  
Metropolitan Area Agency on Aging

**Barbara Babbitt**  
Health Advocates

**Marty Barnum**  
Deaf Hospice Project

**Chrissy Birdsell**  
Little Brothers, Friends of the Elderly

**Sharon Dardis**  
MCDES

**Iris Freeman**  
Minnesota Alzheimer's Association

**Maria Gomez**  
Department of Human Services

**Diane Graham**  
Minneapolis Veterans Home

**Barb Green**  
Little Brothers, Friends of the Elderly

**Ryan Griffin**  
Minnesota Citizens Concerned for Life

**Robert Held**  
Department of Human Services

**Mary Johnson**  
Department of Health

**Sharon Limesand**  
Medica

**Nona Magnuson**  
Hospice of Murray County

**Deborah Maruska**  
Minnesota Senior Health Options

**Mary McGurran**  
Volunteers of America

**Nancy Meyers**  
Deaf Hospice Project

**Patricia Ohmans**  
Health Advocates

**Dr. Dell Ohrt**  
Medica

**Ruth Parriott**  
American Cancer Society

**Emily Peterson**  
Senior Linkage Line

**Pat Plommen**  
Department of Human Services

**Sandy Rausch**  
Conservator

**Linda Reisdorfer**  
Luverne Community Hospital

**Rochelle Schultz**  
Department of Health

**Peg Smythe**  
Department of Health

**Linda Sutherland**  
Department of Health

**Mary Watson**  
Minnesota Association for Guardianship  
and Conservatorship

**Bonnie Wendt**  
Department of Health

**The following people participated in Community Roundtable Discussions:**

**Warren Anderson**  
Mayo Eugenio Litta Children's Hospital

**James Arendt**  
Rantraz Funeral Home

**Robyn Banitt**  
Mahn Family Funeral Home

**Ann Bartlett**  
Mayo Hospice

**Joane Batters**  
Region Five Health Care Task Force

**Karolyn Baumann**  
St. Mary's/Duluth Clinic

**Mary Berger**  
St. Mary's/Duluth Clinic

**Louie Bortolon**  
Vine Funeral Home

**Mary Ann Bowman**  
Albert Lea Hospice

**Bea Britz**  
Unity Family Healthcare

**Dianne Brooke**  
St. Mary's/Duluth Clinic

**Kathy Cahill**  
St. Luke's Hospital

**Craig Carlson**  
Lakeshore Lutheran Home

**Sr. Verda Clare**  
St. Mary's/Duluth Clinic

**Mary Connolly**  
St. Mary's/Duluth Clinic

**Deb Cooper**  
St. Mary's/Duluth Clinic

**Helen Cummings**  
Minnesota Board on Aging

**Michelle Eberhardt**  
Riveredge Hospice

**Helen Eisenmenger**  
Mayo Hospice

**Thomas Elliott**  
St. Mary's/Duluth Clinic

**Tana Erbes**  
Riveredge Hospice

**Nancy Flaig**  
St. Mary's/Duluth Clinic

**Sue Fortier**  
St. Mary's/Duluth Clinic

**Larry Fortner**  
The Senior Reporter

**Susan Fuglie**  
Hospice of the Red River Valley

**Charles Gessert**  
St. Mary's/Duluth Clinic

**Vickie Henrickson**  
Chris Jensen Social Services

**Scott Jorgenson**  
Mayo Clinic

**Phyllis Knutson**  
St. Francis Medical Center Home

**Sr. Mary Christa Kroening**  
Benedictine Health System

**Carol Lukkari**  
Tri County Hospital Hospice

**Judy Meyer**  
Horizon Health Inc.

**Dr. Timothy Moynihan**  
Mayo Clinic

**Sharon Notch**  
Region Five Health Care Task Force

**Laura Palcher**

**LaRae Palmer**  
Lake Land Hospice

**Dayle Peterson**  
St. Mary's/Duluth Clinic

**Kathryn Sawyer**  
Chris Jensen Social Services

**Sheila Skeals**  
Winona Area Hospice

**Pastor Gregory Garmer**  
French River Lutheran Church

**Donna Good**  
Region Five Health Care Task Force

**Lyle Hoxtell**  
Otter Tail County Public Health

**Ruth Kalk**  
Tri County Hospital Hospice

**Mary Koep**  
Region Five Area Agency on Aging

**Shirley Larson**  
Wilkin County Public Health

**Peggy Martin**  
Unity Family Health Care

**Monica Michenfelder**  
Mayo Hospice

**Jan Nelson**  
St. Mary's/Duluth Clinic

**Jessica Organ**  
Mayo Clinic

**Jeanette Palchev**  
St. Mary's/Duluth Clinic

**Tom Patten**

**Mary Phillips**

**Reverend Brian Schultz**  
St. Michael's Catholic Church

**Bertie Speak**  
Morrison County Public Health

**Jo Spees**  
Mayo Hospice

**Jackie Stevens**  
Lake City Hospice

**Dewey Tautges**  
Crow Wing County Commissioner

**Sylvia Temnitz**  
Winona Area Hospice

**DeeDee Thesenuitz**  
Hospice East Range Team

**Reverend Wes Thompson**

**Katrina Tohey**  
St. Mary's/Duluth Clinic

**Lynn Watson**  
Lake City Hospice

**Caren Winkels**  
Region Five Health Care Task Force

**Margaret Wolters**  
St. Mary's/Duluth Clinic

**Karen Zillox**  
Department of Health

The following people were either interviewed about issues surrounding end of life care in minority and immigrant communities or they helped coordinate the interviews themselves by supplying names of possible community representatives (one interviewee from the Somali community preferred to remain anonymous):

**Siyad Abdullahi**  
Hennepin County

**Kathi Antolak**  
Center for Victims of Torture

**Hugo Artola**  
Sacred Heart of Jesus Church

**David Berg**  
Fairview Health Service

**Asya Fridland**  
Jewish Family and Children's Services

**Dr. Craig Garrett**  
Hennepin County Medical Center

**Jose Gonzalez**

**Soyini Guyton**

**Father Larry Hubbard**  
Sacred Heart of Jesus Church

**Jacquelyn Jeunai**  
Health East

**Penda Kane**  
Living at Home/Block Nurse Program

**Sharyn Larsen**  
Center for Victims of Torture

**Nachee Lee**  
Hmong Cultural Center

**Debra Levinstein**  
Jewish Family and Children's Services

**Roxanne Struthers**

**Dr. Phua Xiong**  
Model Cities

## APPENDIX 4

### LETTER TO THE NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

The following is a copy of the letter written by the Commission to the National Hospice and Palliative Care Organization supporting their attempts to change legislation around the Medicare Hospice Benefit rules for nurse practitioner billing.

\* \* \*

#### **National Hospice and Palliative Care Organization**

1700 Diagonal Rd., Suite 300  
Alexandria, VA 22314

From: Minnesota Commission on End of Life Care

Re: NHPCO Legislative Agenda

We are writing in support of legislative changes allowing nurse practitioners to provide and bill for certain hospice services as permitted by state law. The Commission has identified this as an issue that poses barriers to timely and appropriate hospice referral.

In Minnesota, nurse practitioners provide much needed services to our elderly and under-served populations. Under current regulation, they are not allowed to bill for services once a patient has enrolled in hospice care under the Medicare Hospice Benefit. Because of this, many nurse practitioners are reluctant to refer patients for needed hospice services. If patients enroll, nurse practitioners are forced to either provide care without reimbursement or transfer care to a provider who can bill for services.

We believe that nurse practitioners have a significant role to play in the care of those who are at the end of life. We are encouraged that NHPCO also recognizes their importance and have included this issue on the national legislative agenda.

Sincerely,

Jan Malcolm  
State Commission Co-chair  
Minnesota Commissioner of Health

Barry Baines MD,  
State Commission Co-chair  
Medical Director, Medicare  
Services, UCare

## APPENDIX 5

### PATTERNS AND TRENDS IN DYING IN MINNESOTA

Edward R. Ratner, MD, Department of Medicine, University of Minnesota  
John W. Oswald, PhD, Center for Health Statistics, Minnesota Department of Health

Improving end of life care in Minnesota requires an understanding of how care is currently delivered. In addition to the qualitative description of the range and types of services available for those near the end of life the Commission sought quantitative data on the patterns and trends in care. In particular, the Commission sought information on populations in the state that may have greater than average difficulty in obtaining ideal end of life care.

The data below is the result of an analysis of death certificates for Minnesotans who died in Minnesota from 1989 – 1999, provided by the Minnesota Department of Health.

#### **Demographics of Death in Minnesota**

The *number of deaths* in Minnesota in 1999, the most recent year for which full data is available, was 38,538. Of these, 409 (1.1%) were under 1 year of age, 424 (1.1%) were between 1 and 19 years of age, and 30,717 (79.8%) were 65 years or older. In the latter age group, 13,227 (or 34.4% of total deaths) were 85 years or older.

The *death rate* for Minnesota in 1999 was 807 per 100,000, or just over 0.8% of the population.

From 1998 to 1999, there was an increase in both the absolute number of deaths in Minnesota (up 3.6%) and the death rate (up 2.5%).

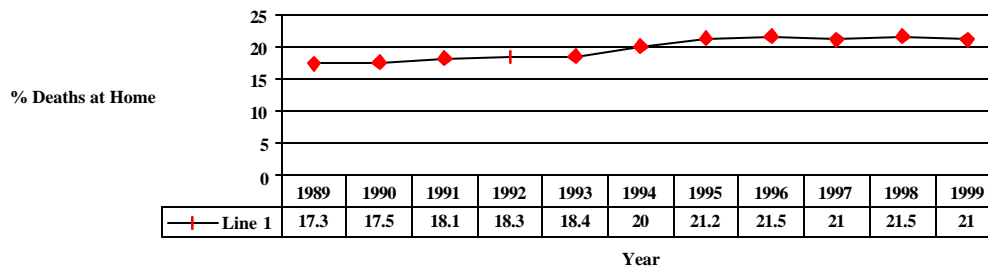
#### **Diagnoses Among those Dying in Minnesota**

Three disease categories – heart, cerebrovascular, and cancer – accounted for two-thirds of all deaths in Minnesota. Violent deaths (including suicide, homicide and unintentional injury) occurred among 2,449 Minnesotans in 1999, or 6.4% of deaths.

#### **Location of Death**

The Minnesota Commission to Improve End of Life Care recognized that a majority of individuals with serious illness prefer to receive end of life care in their place of residence. Death certificates define the location of death as hospital, nursing home, residence, or other. The Commission sought to determine if there is variation in the rate of death at home (i.e., variation over time, across geographic regions, and in defined sub-populations).

The rate of deaths at home in Minnesota rose from 17.3% (5715/32978) in 1989 to 21.0% (7804/37092) in 1999.

**Figure 1. Deaths at Home in Minnesota 1989-1999 (100% sample)**

The rates of death occurring at home in 1999 differed considerably across the 87 counties in Minnesota. See Table 1. These ranged from 8.3% in Rock County to 34.1% in Clay County. Remarkable differences exist even among similar sized counties and within the seven Twin Cities metropolitan-area counties.

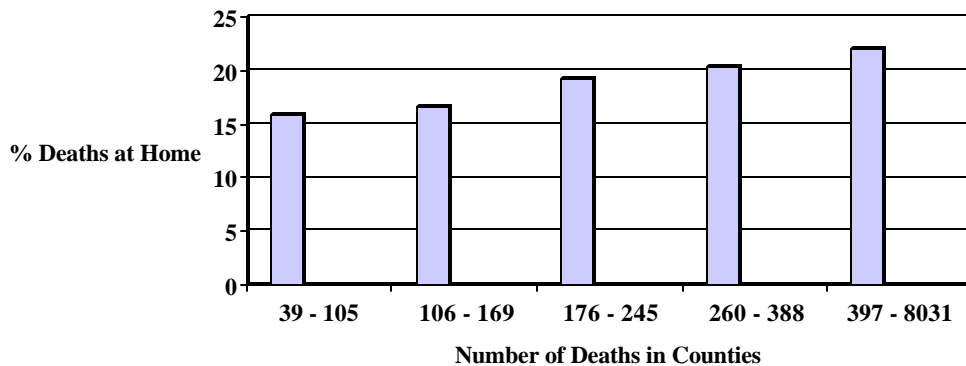
**Table 1. Rates of Death at Home by Minnesota County, 1999 (100% sample)**

County	% Dying at Home	Total Deaths	County	% Dying at Home	Total Deaths
Aitken	20.1	169	Meeker	20.8	231
Anoka	31.8	1306	Mille Lacs	18.0	245
Becker	26.9	260	Morrison	23.6	276
Beltrami	21.9	310	Mower	19.7	468
Benton	20.3	311	Murray	13.2	106
Big Stone	11.5	87	Nicollet	19.0	168
Blue Earth	19.5	435	Nobles	22.5	200
Brown	16.8	315	Norman	17.9	67
Carlton	18.6	285	Olmsted	19.2	809
Carver	23.2	315	Otter Tail	21.5	587
Cass	21.0	295	Pennington	19.0	142
Chippewa	14.5	145	Pine	16.5	236
Chisago	21.6	292	Pipestone	16.5	103
Clay	34.1	226	Polk	28.2	308
Clearwater	12.9	101	Pope	13.9	151
Cook	10.9	46	Ramsey	22.3	4120
Cottonwood	22.4	161	Red Lake	21.3	47
Crow Wing	24.8	512	Redwood	20.2	218
Dakota	26.4	1526	Renville	14.8	209
Dodge	19.5	133	Rice	21.5	404
Douglas	18.9	312	Rock	8.3	96
Faribault	15.5	206	Roseau	16.0	119
Fillmore	18.9	243	St. Louis	19.1	2245
Freeborn	13.1	388	Scott	27.6	381
Goodhue	13.5	481	Sherburne	19.9	352
Grant	19.6	92	Sibley	13.9	151

Hennepin	21.2	8002	Stearns	21.8	762
Houston	20.8	144	Steele	16.3	270
Hubbard	28.0	175	Stevens	10.0	90
Isanti	18.1	215	Swift	9.5	126
Itasca	25.3	438	Todd	16.3	221
Jackson	15.2	105	Traverse	9.4	64
Kanabec	23.8	143	Wabasha	19.0	184
Kandiyohi	14.37	373	Wadena	14.4	194
Kittson	13.6	66	Waseca	17.9	179
Koochiching	16.3	184	Washington	29.8	928
Lac Qui Parle	10.9	138	Watowan	13.1	130
Lake	17.4	121	Wilkin	15.7	70
Lake of the Woods	20.5	39	Winona	17.9	396
Le Sueur	16.7	227	Wright	20.1	541
Lincoln	16.9	89	Yellow Medicine	15.2	132
Lyon	18.5	200	Unknown	0	1
McLeod	13.6	331			
Mahnomen	32.6	43			
Marshall	17.5	80			
Martin	18.8	245			

There was evidence of a trend relating the number of deaths in a county to the rate of death at home. Counties with smaller numbers of total deaths in 1999 had relatively fewer deaths at home compared to counties with more deaths ( $r = 0.187, p < .09$ ). This trend is illustrated in Figure 3.

**Figure 3. Deaths in Minnesota Counties, 1999, by quintile of county size, as defined by number of deaths in county (n=37,092)**



Rates of death at home across racial groups did not vary significantly. Rates were slightly higher among communities of color compared to the white, non-Hispanic population.

**Table 2: Percent Dying at Home by Racial Group in Minnesota, 1999**

White	Black	American Indian	Asian American	Latino
20.9	24.3	26.8	23.5	20.4

Individuals born in the United States and territories were found to have a higher rate of death at home compared to immigrants, 21.2% versus 18.9%, respectively. This difference is primarily accounted for by higher rates of death in nursing homes among immigrants. Rates of deaths in the hospital between the two groups were 30.4% and 29.8%, respectively.

### Overview and Analysis of Findings

A variety of organizations have recommended that the site of death might be a marker for quality of end of life care (*Journal of American Geriatrics Society*, Volume 45, 526-527, 1997). This study of patterns of care at the end of life in Minnesota show the value of such a marker.

In Minnesota, the rate of death at home went up by about four percentage points from 1989 to 1999. In absolute terms, this was an increase of 2089 deaths at home, or an approximately 37% relative increase in the number of deaths at home. This represents a meaningful increase in the demand for home-based resources for end of life care.

Notably, half of the increase in rate of death at home occurred over three years in the middle of this 11-year period (1993-1995). This might be attributed to the creation or focused expansion of home-based end of life services during those three years. For example, if several new hospice programs opened in 1993, rates of death at home could have increased for several years and then stabilized as the previously unmet demand for home-based services was fulfilled.

There is a remarkable four-fold difference in the rates of death at home across counties in Minnesota. Even in the seven-county metropolitan area, there is a 50% difference in home death rates across counties. These differences are unlikely to be related to differences in causes of death or patient preferences, given the relative ethnic homogeneity of the Minnesota population across the state. Possible reasons include geographic variation in access to or quality of home-based health care and home hospice services, as well as variation in the attitudes of physicians and other health care providers.

Immigrant populations in Minnesota have a lower rate of death at home compared to the native born population. The reasons for this are uncertain, but may include differences in

patient preference, access to family caregivers, or financial ability to organize care at home versus in a government funded nursing home.

It is notable that among individuals of African-American, Native American, and Asian communities, rates of death at home are slightly higher than that for the white population. One possible explanation is that these minority groups have greater access to family members who can and will provide home based caregiving at the end of life. An important and currently unanswered question is whether the usage rate for such formal home-based health services as home care agencies or hospice programs, differs among racial groups. It is possible that minority groups are underserved by our health care system, despite similar at-home death rates compared to the white majority.

### **Future Studies**

The findings described above suggest the need for follow-up analyses. Such studies could help to: (1) determine the causes for variation in rates of death at home; (2) develop targeted interventions to raise rates; and (3) monitor changes in these rates over time as a way of assessing the long-term impact of the recommendations of the Commission on End of Life Care.