

ENSURING EXCELLENCE IN END-OF-LIFE CARE/PALLIATIVE CARE

ROCHESTER HEALTH CARE FORUM REPORT TO THE ROCHESTER COMMUNITY

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BACKGROUND

Our community has experienced a year of grief and loss ranging from the closing of The Genesee Hospital to the national tragedy of September 11, 2001. We are called upon to “normalcy” but we will never be the same. It is imperative that we learn lessons from this year and equally important that we heal our spirits. As we deal with these national and local losses, we must also be mindful of the personal needs of the families of more than 6000 individuals that die annually in our community.

Members of the Rochester Health Care Forum Initiative to Ensure Excellence in End-of-Life Care/Palliative Care recognize that our community has a unique opportunity to participate in bereavement in a collective fashion and in doing so, assist individuals and our community-at-large as well. As we grieve our losses, we have the opportunity to have an open discussion on death and encourage community conversations about a subject that is often too hard to face.

The Institute of Medicine Report, entitled **APPROACHING DEATH Improving Care at the End-of-Life** issued a call to action for quality improvement. As defined by the Institute of Medicine, “Palliative Care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure. Palliative Care in this broad sense is not restricted to those dying or those enrolled in a hospice program. It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”

Palliative Care affirms life and regards dying as a normal process. Death is neither hastened nor postponed. An interdisciplinary team approach that integrates psychological and spiritual care seeks to provide relief from pain and other symptoms and provide a support system for the family.

In 1999, the Rochester Independent Practice Association in conjunction with BlueCross BlueShield of the Rochester Area (BCBSRA) each identified “End-of-Life Care/Palliative Care” as a key focus for quality improvement efforts.

A joint RIPA/BCBSRA Professional Advisory Committee was formed to collaborate and identify means of improving the quality of care at the end-of-life. A community-wide survey was identified as the first step. A survey was designed and distributed to local hospitals, home care agencies, hospices, disease management programs and nursing homes. In January, 2001, the survey report (based on a response rate of 50%) revealed that only 38% of hospital patients, 40% of clients in one home care agency, and 72% of residents in our communities' skilled nursing facilities have advance directives in place. Approximately 40% of hospice patients die within seven days of referral to a hospice program precluding the ability of these patients and their families to benefit from the wide array of social, spiritual and psychological benefits that hospice provides.

People are not dying where they want to die. A 1997 D & C survey asked, "If you had a terminal illness, where would you choose to die?" 65% indicated their preference to die at home, 4.4% indicated the hospital and 26.4 percent indicated hospice. In 1999, there were 6257 deaths in Monroe County; 39% died in a hospital-inpatient setting; 33% died in another institution, primarily nursing homes, and only 17% in their own home. Since most people die in an institution, are our institutions prepared to help people die with dignity honoring their values and wishes? Can we provide individuals with the needed support to die at home?

Most people do not die suddenly. Therefore, they have time to communicate their wishes to others who are then able to help them die with dignity in the manner in which they desire. However, in a survey of seniors conducted by BCBSRA this past year, 40% of seniors indicated that their physicians had not addressed the issue of advance care planning despite the fact that 75% of deaths in Monroe County in 1998 were of individuals age 65+.

Death is something we will all face. The same D & C survey questioned, "What are your own worst fears about dying from a prolonged terminal illness?" Members of our community indicated:

82.9% loss of control or dignity

75.2% being in severe pain

62.3% receiving treatment you do not want

40.4% not receiving treatment you do want

People are afraid to die in pain and without dignity or control. The challenge is how do we make this life transition better for all individuals and their families in our community.

The Community-Wide End-of-Life Survey Report was presented to the Rochester Health Commission and the Rochester Health Care Forum Leadership and the initiative was added to the forum in March, 2001. A community-wide advisory group was formed and charged with setting direction for, overseeing, and ensuring the implementation of a set of broad End-of-Life/Palliative Care

projects. The recommendations summarized in the report served as the starting point for the advisory group. These included:

1. Everyone should have an opportunity to complete a comprehensive Advance Care Directive.
2. The health care community should adopt a comprehensive advance care directive that all area practitioners and institutions will honor.
3. Patients should be referred to Hospice earlier so that the social, spiritual and psychological components of suffering can be addressed.
4. Practitioners and Health Care Facilities should establish comprehensive pain assessment and treatment standards at every site of care.
5. Health Care Institutions should be encouraged to set performance goals and track basic statistics regarding end-of-life care.

To assist the Advisory Group and gather community input, four workgroups were formed:

Workgroup 1 Exploring and communicating treatment wishes

Workgroup 2 Ensuring patient wishes are identified and honored at all sites of care

Workgroup 3 Relieving physical, psychological, spiritual symptoms and providing patient/family support

Workgroup 4 Facilitating communication and education, both community and professional.

Death is not an option. It is in allowing the conversation to focus on Death that we can begin to truly experience and appreciate life. As we face the word openly, we recognize and accept our own vulnerability. However, we can also begin to truly live each day to the fullest, appreciate our relationships with each other, share our differences (whether cultural, spiritual, professional or otherwise) and recognize our similarities. In doing so, we can care for each other as if we were family, as indeed we are.

In today's world, health care innovation is most often defined by what can be achieved through the science of medicine and technology. There is much that can be achieved through the art of compassion, collaboration and communication. This is the heart of the initiative to ensure excellence in End-of-Life Care/Palliative Care

VISION

The Greater Rochester Area will be a preeminent leader in providing dignified access to high quality hospice and palliative care services and for ensuring excellence in the provision of health care for those who are approaching the end of their life.

MISSION

The Community-Wide End-of-Life/Palliative Care Advisory Group will serve as a steering committee charged with setting direction for, overseeing and ensuring implementation of a set of broad end-of-life/palliative care projects that result in quality improvements in the lives of those facing death. Our efforts will be replicated and provide clinical and evidence-based research on providing care at the end-of-life.

CORE PRINCIPLES FOR END-OF-LIFE CARE

We adopt these principles of care of patients at the end-of-life:

1. Respect the dignity of both patient and caregivers
2. Be sensitive to and respectful of the patient's and family's wishes ensuring that the patient's personal goals of care are met
3. Use the most appropriate measures that are consistent with patient choices
4. Make alleviation of pain and other physical symptoms a high priority
5. Recognize that good care for the dying person requires quality medical care, but also entails services that are family and community-based and that psychological, social, and spiritual/religious needs must be assessed and addressed
6. Make continuity of care a priority, (the patient ought to be cared for, if so desired, by his/her primary care and specialist providers), but provide palliative care consultation services where desired
7. Advocate access to therapies which are reasonably expected to improve the patient's quality of life, and ensure that patients who choose alternative or nontraditional treatments not be abandoned
8. Provide access to palliative care and hospice care
9. Respect the patient's right to refuse treatment, as expressed by the patient or their health care proxy
10. Respect the physician's professional responsibility, judgment and recommendations to discontinue some treatments when appropriate, with consideration for both patient and family preferences
11. Provide clinical and evidence-based research on providing care at the end-of-life
12. Recognize that although medical care has a critical role to play in supporting patients and their families at End-of-Life, dying is fundamentally a profoundly personal experience and part of the life cycle
13. Assure patients that they will not be abandoned
14. Assist caregivers and care providers with the bereavement process, throughout the stages of mourning and adjustment
15. Provide all members of our community with the opportunity to discuss and plan for end-of-life care
16. Provide culturally competent end-of-life/palliative care in a manner that recognizes the cultural background of the patient and the family.

EXPLORING AND COMMUNICATING TREATMENT WISHES

LONG TERM GOALS

1. Every adult (at least 18 years of age) in Greater Rochester Area will identify in writing the person they choose to speak for them and make decisions about medical conditions when they are unable to speak for themselves in the future (Health Care Proxy).
2. Every adult will have meaningful discussions with their proxy, family and personal physicians about their wishes as they pertain to end-of-life/palliative care.
3. Every adult will have access to an easily recognizable document so that every individual can identify this person. This document will express how a person wishes to be treated if he/she is seriously ill and unable to speak for himself/herself. It will address medical, personal, emotional and spiritual needs.
4. Every adult will have access to educational sessions about planning for future health care decisions as well as meaningful discussions about approaches to care at the end-of life. These will occur routinely in senior living communities, houses of worship, community organizations, doctor's offices, hospitals and nursing homes.

ENSURING PATIENT WISHES ARE IDENTIFIED AND HONORED AT ALL SITES OF CARE

LONG TERM GOALS

1. Every individual with a life threatening illness or chronic disease will have completed an Advance Care Directive describing their wishes, goals of care, values and beliefs.
2. Every individual will have their wishes, goals of care, values and beliefs reviewed and updated periodically.
3. Every individual who is approaching death will have wishes and goals of care honored regardless of the setting in which care is delivered.

4. A uniform community-wide physician orders for life-sustaining treatment form (POLST) or equivalent form will be recognized and accepted in all settings and accompany the patient as they move from one site of care to another.
5. Electronic storage of prepared advance care directives and organ donation information for all patients will be available and accessible to providers.

RELIEVING PHYSICAL, PSYCHOLOGICAL AND SPIRITUAL SYMPTOMS AND PROVIDING PATIENT/FAMILY SUPPORT

LONG TERM GOALS

1. People facing the end-of-life will receive effective pain and symptom management and optimal comfort and support at all sites of care.
2. Principles of Pain Management will be developed that highlight the need to assess and effectively managed pain at all sites of care, throughout the continuum of care.
3. A model of palliative care will be integrated into treatment modalities, beginning at the diagnosis of a life-limiting condition and continuing throughout the course of illness and beyond, regardless of outcome.
4. Best-practice models for delivery of palliative care will be developed at all sites of care.
5. Children living with life-threatening or terminal conditions deserve and will receive intensive symptom management, palliative care, respite programs and services that meet their special needs.
6. Individuals who live with advanced severe illness and die in a long-term care facility are a uniquely vulnerable population who also deserve effective pain and symptom management as well as access to palliative care and hospice care. Their interests at the end-of-life must be defined, protected and advanced.
7. Individuals will be appropriately referred to Hospice earlier to assure that physical, psychological, social, and spiritual/religious needs are met.

FACILITATING COMMUNICATION AND EDUCATION, BOTH COMMUNITY AND PROFESSIONAL

LONG TERM GOALS

1. There will be ongoing broad community dialogue on death, advance care planning, palliative care and hospice care led by and carefully framed by a broad culturally diverse group of consumers and professionals, guided by the core principles for end-of-life care.
2. Community conversations will engage all segments of our society, recognizing the need to reach and to respect people of all ages, as well as diverse cultural and spiritual backgrounds.
3. Multiple channels of communication will be utilized to effectively reach all segments of our community.
4. Educational sessions about planning for future health care decisions as well as meaningful discussions about approaches to care at the end-of life will occur routinely in senior living communities, houses of worship, community organizations, doctor's offices, hospitals and nursing homes.
5. Educational information will be readily available for all members of our community.
6. Professional educational programs like Education for Physicians on End-of-Life Care (EPEC) will continue to be offered to physicians, nurses, social workers, clergy and other health care professionals to address gaps in knowledge, skills and attitudes.
7. Standardized, high-quality education about Death and Dying will be part of the curriculum in middle schools, high schools and adult continuing education programs.

NEXT STEPS

From the inception of forming this initiative, professional and community members of the Advisory Group as well as the Workgroups agreed upon the need to ensure that the work of this initiative would extend indefinitely. All agreed that there is much work to be done and the need to engage and embrace the community-at-large in order to meet the long-term goals. At the same time, the need to begin concrete projects was expressed. The initial projects are as follows:

1. **Community Conversations on Compassionate Care, 2002** will begin with multiple roundtable discussions addressing the diverse segments of our community. The goals will be to increase comfort level in discussing death and dying, to broaden the awareness of the initiative and gain community input, and to focus discussion on conversations that will lead to the completion of an Advance Care Directive (Health Care Proxy/Living Will/optional Organ Donation). This will be framed as a gift-giving project for the fall.
2. A **Physician Orders for Life-Sustaining Treatment (POLST)** or equivalent form that functions as a physician order sheet will be developed. This form will promote patient autonomy, enhance authorized transfer of information and clarify treatment intentions.

A **Life Info Pak (Vial of Life)** that contains emergency information will be developed to facilitate appropriate treatment by emergency personnel.

3. **Principles of Pain Management** will be developed and distributed broadly in the community to assure that pain is assessed and effectively managed across the continuum of care.
4. An **interactive community website**, www.compassionatecare.net, will be launched and developed to serve as a community resource for the dissemination of information.