Palliative Care Resource Paper for Rural Faith Leaders

Introduction:
When someone within your faith community lives with a serious illness, it is important to be aware of palliative care. Due to the fact that the person within your faith-specific care takes on a patient role during their illness process, I will refer to this person as a patient from this point onward in this paper for the ease of referent designation.

Palliative care is for people who seek to relieve their suffering and improve their quality of their life while living with a life-limiting and possibly life-threatening illness. Such patients and their families often face increased pain and symptom management concerns and have an increased need for coordinated care, which includes psychosocial and spiritual support. The following website will enable you to be more familiar with what palliative care is, as well as to acquaint you with some of the language and terminology used within this sphere of care. Also available on this site are more developed descriptions of elements of palliative care such as how hospice is a type of palliative care occurring only at the last stages of life, and the difference made by a team approach to palliative care, as well as many other useful links.

- Center to Advance Palliative Care: www.getpalliativecare.org – Excellent introduction to palliative care designed with patients and families in mind.

Spiritual Care:
Your partnership with a palliative team is vital, given your knowledge of the patient’s story and components of their personhood. Because of your history and relationship with the patient, you are also able to recognize or converse about whether and how they might be suffering. Given your shared faith-specific values with the patient, you are also well suited to assess as you provide your care. If the patient is experiencing spiritual distress, for example, your trusted role and actions offered to mitigate this distress is of much benefit. Your care is something you and your faith community provide to connect the patient with that which collectively gives you a sense of meaning, comfort and transcendence. If a chaplain is a part of the palliative team, he or she will also be able to collaborate with and support your crucial role with the patient. While members of the palliative team may not share your religion, they are committed to spiritually support the patient and their family.

Spiritual care occurs when the palliative team becomes a part of and attends to the patient and his or her story. By attending to a patient’s story, an illness is not cared for,
a person is. When a person, in the midst of serious illness, becomes known, his or her hopes, dreams, challenges, sorrows, passions and joys - their spirit - are shared. Spiritual care, then, is something to which each person on the palliative team contributes by virtue of the skilled healing each team member provides. Together with the palliative team you and your faith-specific care create a sense of shared spiritual care. Depending on your geographic context, the specific palliative team members may vary. Physicians, nurses and social workers are trained to conduct, at minimum, a spiritual screen, and possibly a spiritual history. A spiritual screen is a brief evaluation to discern if the patient is in religious or spiritual distress. A spiritual history is more descriptive data that may relate to the patient’s affiliation with your faith community and how the palliative team might support their spirituality. If a chaplain is involved on the palliative team, he or she is an expert in spiritual assessment conducted through an in-depth interaction. You, knowing the patient’s beliefs and values, would be ideally situated to offer a spiritual assessment as well. You’ll also, based upon your assessment, be uniquely equipped to share such acts as a prayer or a ritual that would address the patient’s particular situation within the specificity of your shared sense of significance and faith.

The following websites are specifically devoted to spiritual care in palliative care and can better enable your interactions with the patient as well as with the palliative team.

- **SOERC (The Spirituality and Health Online Education and Resource Center)** sponsored by The George Washington Institute for Spirituality and Health. This site makes information available related to both palliative care and spiritual assessment. [http://www.gwumc.edu/gwish/soerce/about.cfm](http://www.gwumc.edu/gwish/soerce/about.cfm)

- **HealthCare Chaplaincy**: “A national leader in the research, education and practice of spirit-centered palliative care, which reduces suffering and helps people with life-altering illness to live well and live fully.” Good information about spirituality and palliative care as well as many links to other related organizations. [http://www.healthcarechaplaincy.org/palliative-care-key-facts.html](http://www.healthcarechaplaincy.org/palliative-care-key-facts.html)

### Partners in Care:

Connected with your faith-specific care, the palliative team is also interested in what you did with the patient, what happened and what you plan to do next. Did you, for example, intentionally address their suffering and enhance their quality of life? Because palliative care occurs in many different settings from inpatient care within a hospital, to the outpatient clinic or care provided at home, your access to the person within your faith-specific care is important. Your communication with the palliative care clinicians is significant as well. Due to the confidentiality and privacy laws, it is necessary for the patient within your care to grant permission in order that you and the palliative care team may be able to communicate with one another. However, if for instance, a family
care conference is held, your presence there and possible contributions would be of much value given your relationship with the patient and their family.

**Advocacy**

Your contributions to the advocacy of palliative care within your faith community can help people live with life-limiting, serious illness hear the good news that their suffering can be reduced and the quality of their life enhanced. Much of this begins with you, the language you use and the meanings you apply to palliative care within your community long before people become patients with serious illness. Because of you and your role, your faith community may understand that there is something we can do when someone is suffering, and that though a life is altered by serious illness, a life of profound meaning can still be claimed as it is accompanied through difficulty and joy.

Another practical way you can advocate for palliative care is related to the completion of health care directives. This document is much more than people individually indicating their resuscitation preference should they be unable to make a decision for themselves. Instead, it is an opportunity for their identity, values and beliefs about their life and health to be stated and upheld when the need arises. Below is information about an initiative to support people in the completion of their health care directives.

- **Honoring Choices Minnesota:** This initiative is led by the Twin Cities Medical Society and seeks to facilitate the growth and expansion of people having discussions about advance care planning. There is a free downloadable health care directive at this website as well.
  

When advance care planning happens, conversations occur and stories are told. When the story of serious illness enters the life of those for whom you care, your involvement is vital to the faith and spirituality of the patient, and as a result to the palliative care team as well. This is particularly true when the patient may be dying and challenging choices emerge. For example, the patient and family may need to address whether to withdraw or withhold measures if not providing a benefit, but instead being a burden. As the patient’s faith leader many patients seek your faith-specific guidance in the muddy water of hard choices and complex decision making. Chaplain Hank Dunn has written a useful and thorough resource related to helping you navigate these matters as you support the patient and family within your care.

- **Hard Choices for Loving People, 5th Edition:** It is available for free to patients and families through the website. [http://www.hardchoices.com/](http://www.hardchoices.com/)
Recommended Resources

Books

Journal Article

About the Author
Paul Galchutt, MDiv BCC, serves as the inpatient Palliative Consult Service chaplain at the University of Minnesota Medical Center (UMMC), Fairview. Paul also has experience as both a Critical Incident Stress Management and bereavement coordinator. Prior to chaplaincy he served seven years as a Lutheran (ELCA) congregational pastor. Paul can be reached at pgalchu1@fairview.org or 612-273-3912.

9/19/2011