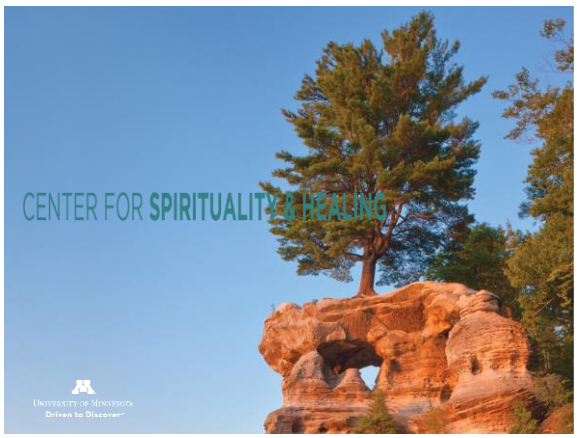

Living Well, Dying Well

Center For Spirituality & Healing

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What is Living Well, Dying Well?

Living Well, Dying Well (LWDW) is an initiative of the Center for Spirituality & Healing, that provides individuals, their loved ones and healthcare team members with tools, education and resources to empower communication for effective End Of Life (EOL) care in a range of healthcare settings.

The goal of LWDW is to facilitate effective communication in EOL care so that individuals can live as well as possible and die as well as possible.

The 4 Pillars of Living Well, Dying Well

1) Academic course (2 credits) through the Center For Spirituality & Healing. Next class: CSH 5000, Fall Semester 2016

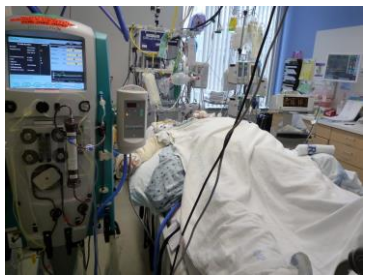
2) Community education and engagement

3) On-site continuing education for healthcare professionals

4) Ongoing program evaluation, research and evidence around communication in EOL care

What We Hope for in our EOL Care

What We Often Receive for our EOL Care



Background

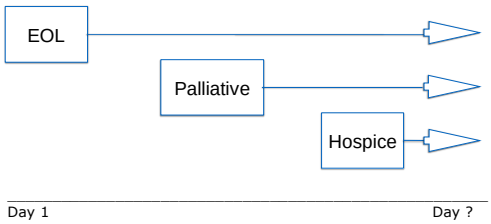
- Dying in America is fragmented, expensive, and hospital-based
- >70% of Americans die from a chronic disease
- >80% want to avoid hospitalization and intensive care at the end of life
- Medicare recipients will be hospitalized >1.5 times during their last 6 months
- 33% of Americans see >10 physicians during their last 6 months
- 15% of Medicare recipients admitted to ICU for >1 week during last 6 months

Healthcare team members are challenged to initiate and support EOL communication:

1) Lack of education in initiating and sustaining effective communication.
2) Patient preferences, difficult to infer, need to be regularly assessed.
3) Every team member who works with patients or their loved ones around EOL care needs support and empowerment.
4) The mental, physical, and emotional impact of providing EOL care on staff can lead to burnout and turnover.
5) The lack of communication can have a negative impact on EOL care, including utilization.

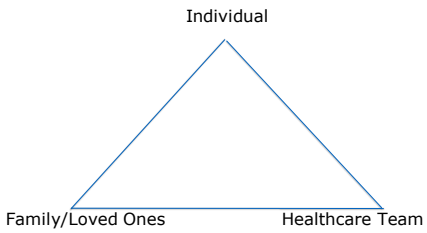
Galushko et. al., (2012) . Challenges in end-of-life communication, *Current Opinion in Supportive & Palliative Care*; 6(3)355-64, http://www.ncbi.nlm.nih.gov/pubmed/22871981?dopt=Abstract&holding=f1000,f1000m,isrctn

How does EOL communication fit into the continuum of care for patients and families?



Intake/Admission
Discharge/Death

EOL care encompasses everyone around the healthcare triangle:



Living Well, Dying Well Academic Course:

The curriculum incorporates three facets of communication about end of life care:

(1) Living Well: Reflecting on and articulating how we want to make the most of our lives, using the Wellbeing model

(2) Dying Well: Communicating choices, values and beliefs around end of life care with those who care for and about us

(3) Being There: Educating, equipping and supporting healthcare team members in effective communication around EOL care and how to care for themselves

LWDW Learning Objectives

Demonstrate effective communication with individuals and their families at crucial times, raising and addressing questions, concerns, and decisions regarding care choices toward the end of life.

Identify techniques for coping with fear and anxiety in EOL care, including exploring personal attitudes and perspectives about EOL.

Explore individuals' definition of living well, including family, faith, and culture; encouraging individuals to articulate their vision of living well: goals, dreams, hopes, meaning & purpose.

Explore individuals' definition of dying well, including questions, fears, anxieties and personal experiences with death and dying.

Identify and clarify an individual's goals of care in a person-centered advanced care plan

Identify techniques for "being present" for individuals and their families in EOL care, including self-care strategies to cope with EOL care and ways to enhance the EOL care work environment

LWDW Content Overview

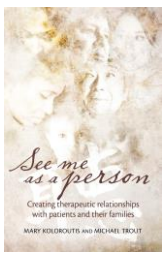
1 - Empowering Communication through Therapeutic Relationships

2 - Assessing Psycho-Spiritual Health; Role of Culture in Communication and Decision Making

3 - Exploring Personal Perspectives on End of Life; Self-care as Integral to EOL Caregiving

4 - Goals of Care and Planning

5 - Putting It All Together: Integrated EOL Care



The core resource:

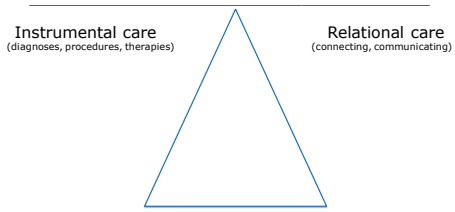
See Me As A Person

M. Koloroutis & M. Trout

(2012)

*Award-winning book on healthcare communication

LWDW EOL Care communication based on a therapeutic relationship, a balance point between



Why a Therapeutic Relationship?

Maintains providers' professional boundaries while giving access to patients/individuals' emotional, mental and spiritual health

Allows patients/individuals to communicate effectively in a care setting centered on their goals, values, choices.

Jourard: patients and families experienced a lack of caring, or healing relationship when providers performed care in a ritualized, scripted manner.

Jourard: verbal interactions between providers, patients and families yielded as much valuable information about effective care as diagnostic tests and procedures.

Providers often focus on either instrumental care or relational care. Therapeutic relationship uses both in balance.

Ongoing Psycho-Spiritual Assessment

- What questions might you ask to wonder about a patient or family/loved one's psycho-spiritual health?
- Assumptions cut off any assessment, stop health professionals from listening. E.g.: Patients who identify as strongly religious are at peace with dying and "ready to go." Yet, research shows the opposite is true
- Open-ended questions are crucial to assessment: E.g..: "What do I need to know about you as you approach the end of your life?" "Do you have any requests or needs as you approach the end of your life?"
- Simple values clarification exercise are also helpful: Go-Wish card game, or My Gift of Grace exercise
- The range of questions you ask depends on the person, their circumstances, their culture, needs and wants

In EOL Care, Culture has Soft Boundaries

- Individuals will pick and choose which parts of their culture they need and want in EOL care, which parts they choose to ignore or discard.
- Some choices will surprise you, others confirm cultural norms. Assumptions can be obstacles to assessment.
- Individuals and their loved ones may differ, even clash over cultural norms, especially within EOL care. Clear communication with the individual is crucial.
- Remaining curious about the individual leads us to the cultural values of that person.

LWDW's 5 or 10 R's of EOL Care

As individuals approach the end of life they may experience some of the following, both externally and internally:

1) **Review/Remember** - life, relationships, events, places.

2) **Reconcile/Release** - relationships, dreams/hopes, goals, forgiveness of self and others.

3) **Resignation/Relief** - may include death & dying.

4) **Rejection/Regret** - may include family, faith. culture, values, "sins of omission & sins of commission," death & dying. Can appear as isolation.

5) **Reverence/Recognition** - may include gratitude, love and appreciation for people, places, things (e.g.: faith, family, friends, church, work, sobriety, etc.)

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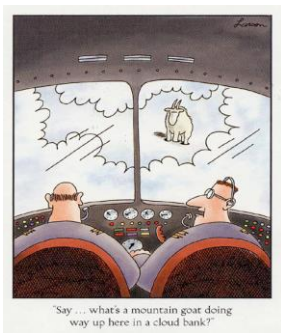
Goals of Care & EOL Planning (GOCP)
< 30% of us won't have to do <u>any</u> GOCP



"Say . . . what's a mountain goat doing way up here in a cloud bank?"

How do we standardize EOL GOCP conversations?

Dr. Susan D. Block, an oncologist at the Dana Farber Institute in Boston developed 4 Questions for Goals of Care

(1) What you do you know/understand about your health prognosis?

(2) What do you fear about what is to come?

(3) What are your goals during the time you have left?

(4) What trade-offs are you willing to make between your quality of life and medical treatment to extend your life?

What EOL Care questions would you ask?

Goals of Care and EOL Planning is about having good EOL conversations

"They're not about 'hard choices,' they're about what you look forward to and what you fear."

"They're not about epiphanies, about the answer to a question, they are a process, a series of conversations"

- Dr. Atul Gawande, Mass General Hospital

LWDW Faculty

Frank Bennett, Senior Fellow and program leader for Living Well/ Dying Well at the Center For Spirituality & Healing, University of Minnesota. He is an ordained United Church of Christ minister, chaplain, support group facilitator, teacher, completed 1.5 years of CPE training. Spiritual care professional in acute, palliative and hospice care settings. He focuses on supporting and educating everyone involved in end of life care. Committed to providing humane care for each person, regardless of culture or beliefs, with a specialization in memory care.

Susan O'Conner-Von, Associate Professor in the School of Nursing, University of Minnesota and Director of Graduate Studies in the Center for Spirituality and Healing. As a nurse educator Susan holds a strong commitment to enhancing the knowledge base of palliative and end-of-life care through teaching and advising of undergraduate and graduate nursing students. Susan completed the AACN / City of Hope ELNEC Train-the-Trainer Pediatric Palliative Care program and the Core (Adult) program. In 2010, she was awarded the March of Dimes Nurse of Year Award in Palliative and Hospice Care, and recently she was awarded 2016 Certified Hospice and Palliative Pediatric Nurse (CHPPN) of the Year.


QUESTIONS?
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