

PLEASE TAKE A MOMENT TO PROVIDE US WITH YOUR ANSWER TO THE FOLLOWING QUESTION
 (use the Q&A tab to share your response, please):

Tell me, what do you plan to do with your one wild and precious life?

—Mary Oliver*

Mary Jane Oliver was a Pulitzer Prize winning American poet. Her work is inspired by nature, rather than the human world, stemming from her lifelong passion for solitary walks in the wild.

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Become a **VCU** Gerontologist

The Cultural, Psychosocial & Spiritual Aspects of End of Life
 Week 3

Instructor: Enid Walker Butler, MSG, CT
 Adjunct Instructor

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MIND DUMP

PARKING LOT **BE HERE NOW**

Before we get started please take out a piece of paper. Draw a line down the center. On the left side write Parking Lot. On the right side write Be Here Now. On the **Parking Lot** side write down all the things swirling in your mind that you need to remember to do but not right now (shopping list, friends to reach out to). On the **Be Here Now** side write down the things that are on your mind about tonight's class (topics of interest, questions you have, ideas to share).

Take this moment to come into this learning space.

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<h2>Course Objective</h2>	<p>To recognize the importance of:</p> <ul style="list-style-type: none">Self-determinationThe uniqueness of the individualThe individuality of death
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<h2>COURSE INSTRUCTOR</h2> <p>Enid Walker Butler Adjunct Instructor Department of Gerontology College of Health Professions Virginia Commonwealth University</p>	
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The Course				
1	2	3	4	5
Week 1 Death and Dying - an Overview	Week 2 Death and Dying in the COVID19 World	Week 3 The Cultural, Spiritual and Psychosocial Aspects of EOL	Week 4 Models of Care and Advance Care Planning	Week 5 Loss and Grief

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WEEK 3 AGENDA

Focus

Welcome

Cultural, Psychosocial and
Spiritual Aspects of EOL

Practice Pause

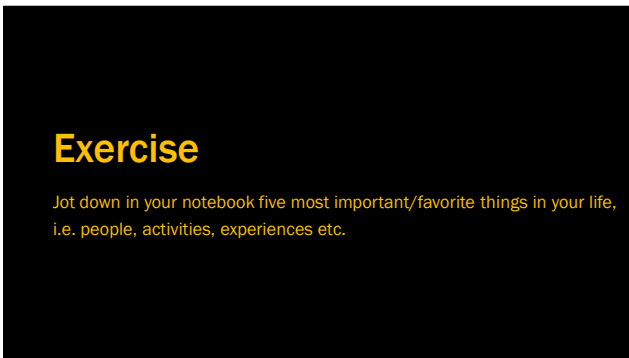
Discussion

Wrap up

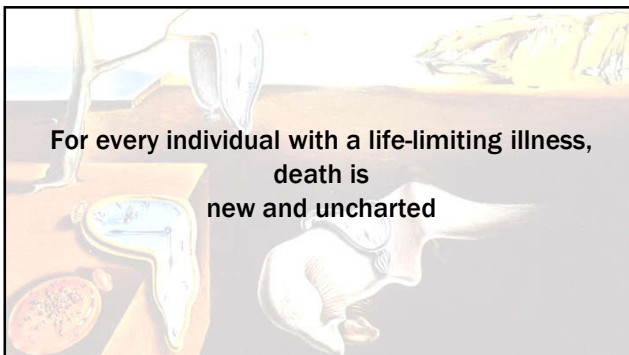
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The terminally ill are living through their dying experience

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Death brings out cultural, religious, ethnic, social, spiritual and economic variations that may be neglected or hidden in other health-care settings.

Families often revert to the customs of their ancestors to provide a sense of continuity during times of loss and grief. They may call upon their personal beliefs and familiar rituals to help them through the tough times surrounding a death.

The Heart of Hospice

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"Care at the end of life should recognize, assess, and address the psychological, social, spiritual/religious issues and cultural norms realizing that different cultures may require significantly different approaches."

American Academy of Family Physicians

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What is Culture?

Common set of ideas, values and expected ways of behavior shared by a people group.

Often passed down through the generations, provides a sense of identification

Most commonly is racial or ethnic in nature but can also include geographic location, faith practices, family patterns, social class, sexual orientation, etc.

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The Context of Culture

Informs our views on both life and death

Influences Is the standard to define and conduct lives.
(Benchmark even if having decided to reject the standard)

Establishes practices valuable to one group/unfamiliar or challenging to another

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United States ... a More Diverse Nation

Ethnic and cultural make-up of US population is changing

Population	2019
Non-Hispanic Whites	60.1%
Hispanic & Latino	18.5%
African American	13.4%
Asian	5.9%

By 2040, 50% of Americans will be non-white.
One out of two patients will come from a non-white background.

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Poll

Do you regularly interact with different cultures in your workplace?
Have you received any diversity or cultural competency education?
Do you feel equipped to provide culturally sensitive care to those you serve?

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Cultural Influence at EOL

General attitudes towards EOL • Taboo or celebrated	Beliefs about pain and suffering • Is suffering to be embraced or avoided?	Role of family Death as family event. • Who cares for our loved one? • Definition of and role of family.
Attitudes towards the healthcare system • Trust vs. distrust • Traditional medicine vs. alternative traditional practices	Decision-making • Paternalistic • Individual • Collective	Communication • Disclosure to patient • Disclosure to family
Religious/spiritual beliefs • Meaning of death • Attitudes towards medical treatment	Funeral customs and rituals • Body preparation • Memorializing	Language Barriers • Can greatly impact clarity of communication.

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Be aware and sensitive to the attitudes, practices and beliefs of a culture group.

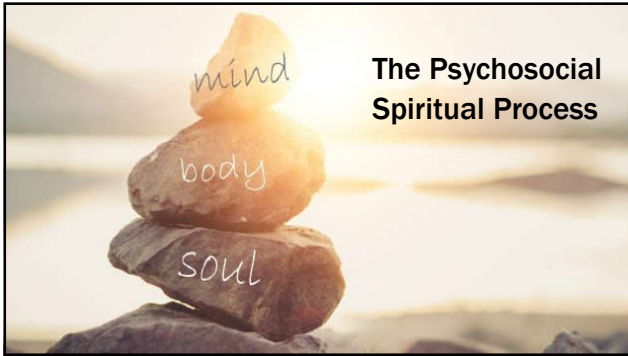
Never assume.

Wide range of individual diversity within cultural groups
May not adhere to cultural norms.

The world we see is only the world as we see it. Others see differently.

Albert Einstein

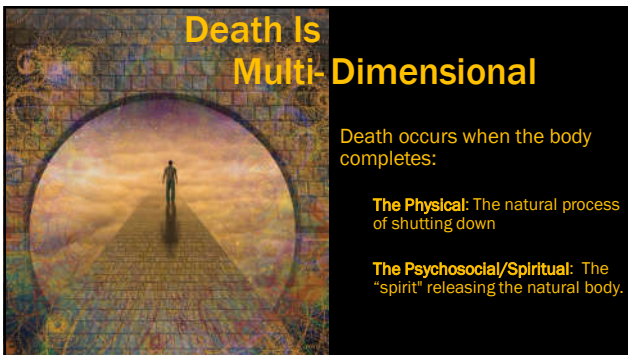
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Death is a
spiritual process with medical implications
rather than a
medical process with spiritual implications.

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The Process

Natural process of emotional, spiritual, mental release

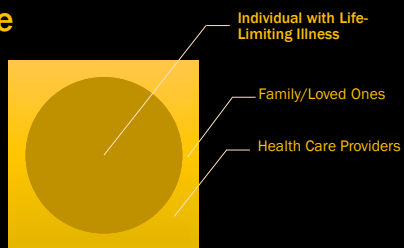
Release of the body and environmental attachments

Prepares spirit to move from this existence to the next

Requires support and encouragement

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Death is a Shared Experience



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The Ethical Principle of Autonomy



Autonomy – self-determination;
“An individual’s ethical right to receive care consistent with their preferences.” (Houska & Loucka, 2018)

Autonomy has a deeper, more contextualized meaning with terminally ill individuals.

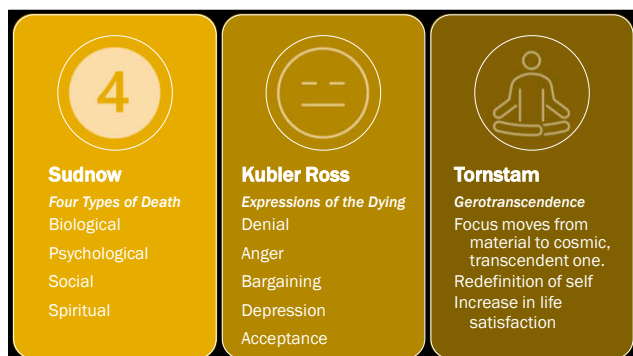
Being Normal Taking Charge

Review of literature reveals the need to view autonomy not just as the ability to make one’s own treatment choices but **to be supported in the process of living through a terminal illness.**

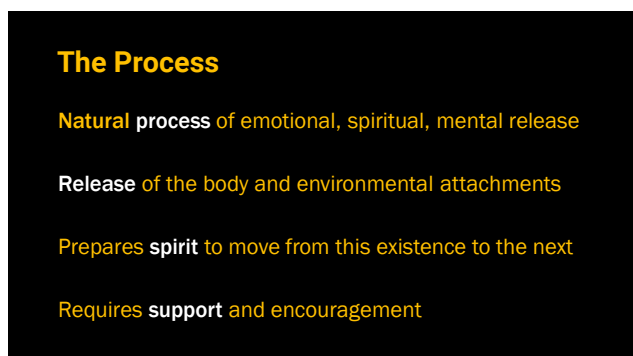
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DID YOU KNOW?

BREAK

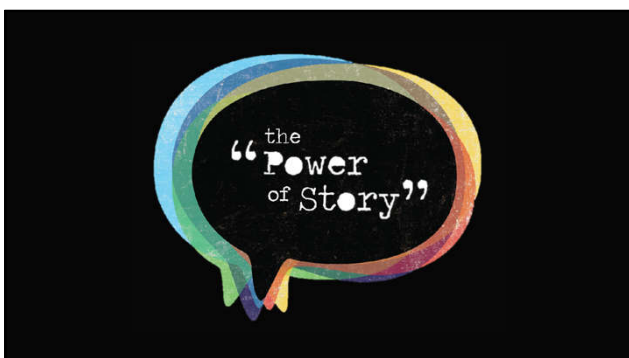
Ars moriendi ("The Art of Dying") are two related Latin texts dating from 1400s, offering advice on the protocols and procedures of a good death, explaining how to "die well" according to Christian precepts of the late Middle Ages.

It was written within the historical context of the effects of the Black Death 60 years earlier and consequent social upheavals of the 15th century.

The earliest versions were most likely composed in southern Germany. It was very popular, translated into most West European languages, and was the first in a western literary tradition of guides to death and dying. About 50,000 copies were printed before 1501 and further editions were printed after 1501.

Its popularity reduced as Erasmus's treatise on preparing for death (*De praeparatione ad mortem*, 1533) became more popular.

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Pain-Free Status *Feeling No Pain*

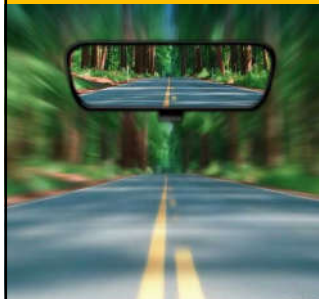
More concern about suffering during the process of dying than death itself.

Symptom control is not just about physical comfort.

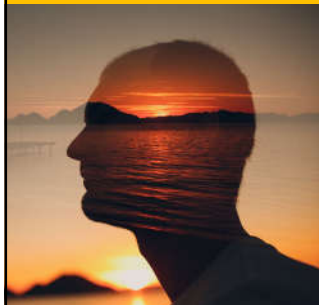
Alignment with overall value systems, such as balancing pain control and cognitive alertness to allow meaningful interaction with loved ones.

Psychosocial and spiritual issues can manifest in biological symptoms.


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<h2>Life Completion</h2>	<h3>Looking Back</h3>
	<p>Developmental task of "Maturity" or "Completion," inner sense of wholeness.</p> <p>Reframing of past conflicts into new meaning (Often, where regrets are expressed.)</p> <p>Attained by introspection and self-reflection that facilitates reconciling one's life choices and achievement.</p> <p>Closure with loved ones – goodbyes, reconciliation/repair of relationships</p>

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<h2>Emotional Well-being</h2>	<h3>Peace of Mind</h3>
	<p>Emotionally and psychologically supported</p> <p>Finding & maintaining inner peace</p> <p>Maintaining and improving close relationships</p> <p>Addressing fear of abandonment.</p> <p>May narrow focus to most valued relationships and activities.</p> <p>Ability to explore meaning of death</p>

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<h2>Dignity</h2>	<h3>A Sense of Worth</h3>
	<p>Ageism and age-related losses devalue perception of worth.</p> <p>Life-threatening illness feelings of loss, lack of value and self-worth.</p> <p>Loss of social and familial roles, loss of future goals and plans.</p> <p>Desire to maintain personal dignity "disease process" or "dying individual."</p> <p>Focus importance of role within the family, sharing of tangible (i.e. money, heirlooms) and intangible gifts (i.e., concern for others, sharing life lessons).</p>

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Quality of Life



A Life Worth Living


“Palatable quality of life” even if limited
 Requires adaptation and redefinition of quality of life
 Combination of symptom management, psychosocial as well as practical support.

As health declines
 illness-related losses and dependence on others increase



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Family



Who Do You Love?

Broad definition of family – blood relatives & loved ones
 Maintaining and improving relationships and interpersonal connections.
 Concerns regarding burden to those left behind.
 Affairs in order.
 Leaving no “unfinished business” with loved ones. Two-Way
 I love you.
 Forgive me.
 I forgive you.
 Thank you.

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Exercise

What were your feelings of loss when you marked off your most important things?

How can we support our clients through these losses?

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Primary and Secondary Loss And End of Life

PRIMARY LOSS
the loss of something or someone significant


Terminal diagnosis
 Death of loved one

SECONDARY LOSS
the accompanying losses that are created or caused by a primary loss; can be as or more painful than the original loss.

Security i.e., financial, emotional
 Future
 Role
 Hopes and dreams

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Spirituality & Religion *Looking Forward*



Something inside of each of us that we define and express as spiritual.

A variety of meanings and expressions.

Spirituality and religion complex overlapping concepts

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Spirituality	Religion
<ul style="list-style-type: none"> • Ways individuals search for and define meaning and experience connectedness. • Connectedness encompasses: idea of God or a higher power, self, others, nature 	<ul style="list-style-type: none"> • Focuses on a relationship with God and others. • Centers around a specific set of doctrines which are practiced by a faith community • Usually involves preparation for and focus on an afterlife.

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Spirituality & Religion

Source of transforming hopelessness into hope, meaning and gratitude.

Significant source of coping, strength, comfort and community

Assurance of being loved

Involves the outcome for the "self;" connected to the unknown and afterlife

Questions around forgiveness, reward or punishment, passage to another life

Individual's spiritual struggle and re-examination of belief systems can look like unbelief

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Transcendence



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Nearing Death Awareness

Broadly defined as life dreams or visions when death is near.

Often misinterpreted as delirium or hallucinations.

Usually comforting and reported with clarity

Presence of someone who has passed

Preparing for change (i.e. completing a task, travel)

Vision of a different realm

Knowing time of death

Death bed visions have been occurring since the beginning of time.

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Reflection for the Week

Have you identified life changes you want to make that will set you on a better path for a good death?

An email will follow with an invitation to share these thoughts.

@VCU Students – these thoughts would be outside your required Journal Entry. Refer to the class Syllabus or reach out to the instructor with questions.

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VCU
College of Health Professions
Gerontology

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