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

If you could write your own obituary, what would the title be?

1

Models of Care Loss & Grief

A Five-week Course

Instructor: Enid Walker Butler, MSG, CT
Adjunct Instructor

2

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.

3

Course Objective

To recognize the importance of:

Self-determination

The uniqueness of the individual

The individuality of death

4

COURSE INSTRUCTOR

Enid Walker Butler

Adjunct Instructor

Department of Gerontology
College of Health Professions
Virginia Commonwealth University

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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** Advance Care Planning and Difficult Conversations	**Week 5** Models of Care Loss and Grief

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WEEK 1 AGENDA

- Focus
- Welcome & Stage Setting
- Death and Dying
- Practice Pause
- Discussion
- Wrap up

7

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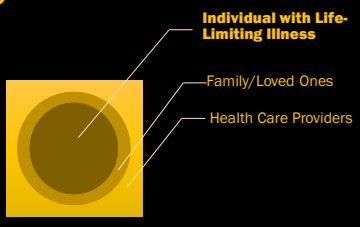
Death is a Shared Experience



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The Notion of a "Good Death"

- **Preferences for the Dying Process** *How Who When Where*
- **Pain Free Status/ Treatment Plan** *Feeling No Pain*
- **Emotional Well Being/Dignity** *Peace of Mind*
- **"Family"** *Who do you love?*
- **Life Completion** *Looking back*
- **Spirituality/Religiosity** *Looking forward*
- **Quality of Life** *A Life Worth Living*

(Meier et al., 2015)

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The Ethical Principle of Autonomy

Being Normal
Taking Charge

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.**

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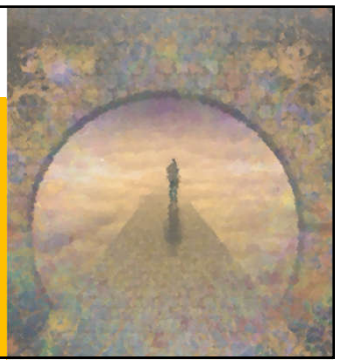
Death is a spiritual process with medical implications
rather than
a medical process with spiritual implications.

12

Death Is Multi-Dimensional

Death occurs when the body completes:

- **The Physical:** the natural process of shutting down
- **The Psychosocial/Spiritual:** the "spirit" releasing the natural body.



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The Psychosocial 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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Models of Care

15

POLL

Have you ever had a loved one pass away

1. At home?
2. In a hospital?
3. In long term care?
4. In hospice care?

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U.S. Overview

2019 Total Annual Deaths: 2.85 million
Deaths 65+: 2.1 million (approx. 74% of US deaths)
Adults 65+: 54.07 million (16.5% of US population)

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	Death in 1900	Death in 2000
Life Expectancy	47.3 years old	78.9 years old (2019)
Cause of Death	Infectious Disease Smallpox, influenza, scarlet fever, pneumonia	Degenerative/Chronic disease Heart disease, cancer, stroke, lung disease, dementia
Trajectory	Rapid, brief (days, weeks)	Slow decline (months, years)
Location	80% at home Only poor died in institutions	62% in institutions, i.e., hospitals, nursing homes
Caregivers	Family Members	Paid Professionals
Death Encounter	Intimate, Close, Participant	Removed, Sanitized, Observer
Role of Physician	Comforter, Consoler	"Curer-er," Miracle Worker

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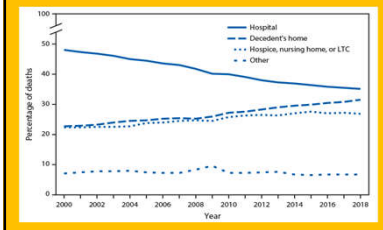
Where Older Adults Die



Hospitals 35.1%
Home 31.4%
LTC 26.8%

Wonder.cdc.gov/ucd-icd10.html

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Hospitals - Acute

35% of older adults die in hospitals, down from 50%.	Disease/Curative Focus	Costly ~$4,000-$10,000 day
May provide a sense of security for some, sense of anxiety for others	Presence of family & loved ones important.	Usage of palliative care important

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Long Term Care

27% of deaths occur in long-term care facilities.	LTC focus of care and reimbursement based on restorative and maintenance goals	EOL requires intense focus on symptom management.	Staff ratios often don't allow for level of care required at EOL.
CNAs, provide majority of hands on care. Know patient Limited training	Family expectations often exceed facility capabilities.	Determining death trajectory complicated.	Stronger partnerships with hospice care.

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Palliative Care

Palliate: to render less harsh or severe without eliminating the cause; to reduce suffering

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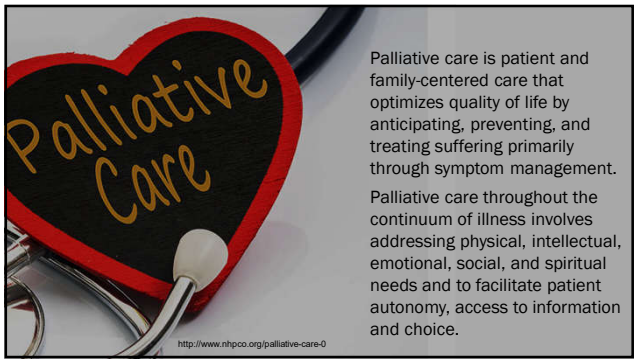

Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering primarily through symptom management.

Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.

http://www.nhpco.org/palliative-care-0

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Palliative Care

Main focus on symptom management	Primarily offered in hospital or outpatient setting	Services provided and coordinated by an interdisciplinary team (medical & psychosocial)
Collaboration between family, providers both medical and psychosocial team members	Services are available concurrently with or independent of curative or life-prolonging care	Reduced medical costs and re-hospitalizations

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All hospice care is palliative
but
all palliative care is not hospice care.

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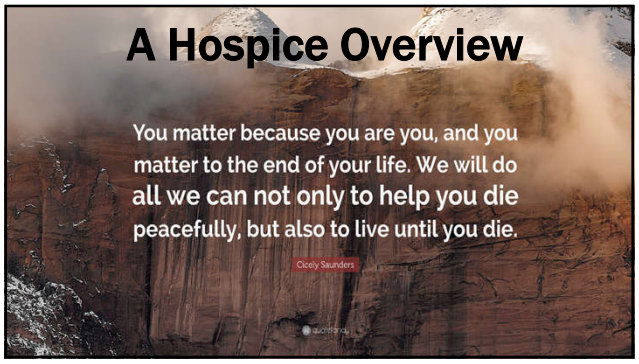

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Hospice is Not a Place

But a holistic model for compassionate, quality care for individuals facing a life-limiting illness or injury.

Word "*hospice*" (same linguistic root as "hospitality") traced back to medieval times; place of rest and shelter for ill or weary travelers.

Hospice is at once both ancient and modern. (Callahan, 2008)

Most widely used form of palliative care.

When a patient hears "nothing more can be done," the hospice team says "much more can be done to support living fully until death."

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Hospice Is About Living

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury

A team-oriented holistic approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.

Support is provided to the patient's loved ones as well.

At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

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History of Hospice

1065
First known hospice begins in Malta caring for ill and dying travelers traveling to the Holy Land.

1967
Dame Cicely Saunders creates St. Christopher's Hospice in England.

1969
Kubler-Ross publishes *On Death and Dying*

1974
Florence Wald founds Connecticut Hospice in Branford, CT.

1986
The Medicare Hospice Benefit is approved by Congress.

2008
First major revision of Medicare Hospice Benefit Conditions of Participation (CoPs) since 1986

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Central to hospice care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

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Principles of Hospice Care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates cultural, psychological and spiritual aspects of patient care.
- Offers support systems to help patients live as actively as possible until death.

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Curative Versus Hospice Care

Curative:

Disease driven
Doctor in charge
Disease process primary
Narrow focus

Hospice

Symptom driven
Patient in charge
Comfort and quality of life primary
Holistic focus

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Hospice Eligibility

Certification by 2 physicians of terminal illness
presence of a disease that would take life in 6 months or less if it follows it normal course

Acceptance of comfort care instead of aggressive treatment for terminal illness

Medicare funds 82% of all hospice care in the US.

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"Wherever Home Is"

Home can be:

Patient's home	Long Term-Care	Hospital	Hospice House
55.7%	42.2% •Independent Living •Assisted Living •Skilled Nursing	0.8%	0.8%

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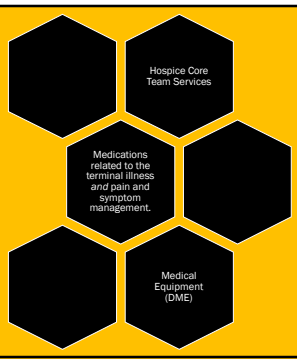

Overview of Services

- Symptom control and pain management
- Support in psychosocial, emotional and spiritual aspects of dying process.
- Medication, supplies and equipment.
- Family caregiver training and support.
- Volunteer support
- Special services as needed (speech, PT)
- Short-term in-patient care for symptom/pain management or family respite.
- Emotional and bereavement support to family.

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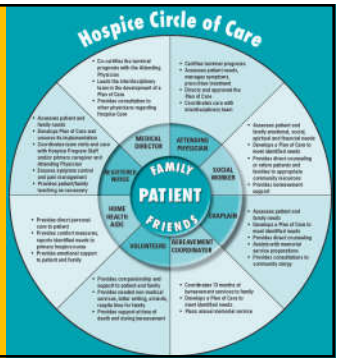
Interdisciplinary Team



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Benefits of Hospice Care

- Extended life over "usual care" patients (approx. 29 days)
- Reduction in overall health care usage
- Reduction in hospitalizations; Less hospital deaths
- Higher care satisfaction (patient and family)
- Higher perceived quality of life
- Families and patients felt more supported and less isolated
- Lessens grief after death

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Barriers to Hospice Care

- Reluctance to terminate life-saving interventions
- Reluctance of health care providers to have the conversation with patients
- Difficulty of determining 6 mth prognosis.
- Stigma
- Misconceptions of how it works
- Social cultural beliefs

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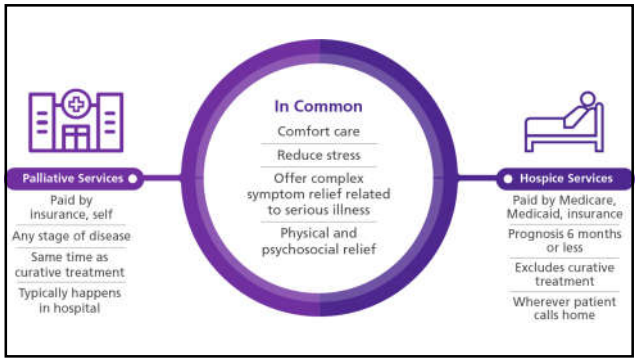

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Break

Nothing Gold Can Stay by Robert Frost

Nature's first green is gold,
Her hardest hue to hold.
Her early leaf's a flower;
But only so an hour.
Then leaf subsides to leaf,
So Eden sank to grief,
So dawn goes down to day
Nothing gold can stay.

**Robert Lee Frost* (1874 – 1963) was an American poet and the only poet to receive four Pulitzer Prizes for Poetry.*

40

Break

Separation by W.S. Merwin

Your absence has gone through me
Like thread through a needle.
Everything I do is stitched with its color.

***William Stanley Merwin** (1927 – 2019) was an American poet who wrote more than fifty books of poetry and prose and produced many works in translation.*

41

Break

The Window by Rumi*

Your body is away from me
but there is a window open
from my heart to yours.

From this window, like the moon
I keep sending news secretly.

**Jalāl ad-Dīn Mohammad Rūmī (1207 – 1273) was a Persian poet, scholar and theologian.*

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Loss & Grief

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Terminology

Loss	•to have something taken that is of value; root meaning "torn or shorn off"
Bereavement	•the event of loss; the period after a death or loss
Grief	•the feelings and thoughts we have when we lose someone; the "container" to hold the experience (Wolfelt, 2018)
Mourning	•to express sorrow or grief outwardly; how we express (or fail to express) our grief. Grief gone "public" (Wolfelt, 2018)

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Primary and Secondary Loss

1

PRIMARY LOSS

the loss of something or someone significant

Terminal diagnosis
Death of loved one

2

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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Primary Types of Grief

Anticipatory Grief	Disenfranchised Grief	Complicated Grief
• Pre-event grief as a result of an expected loss • Does not always occur. • Also, research shows that anticipatory grief does not reduce later grief. • Not a "zero sum game"	• Grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned"	• Complicated grief involves prolonged unresolved feelings, a sense of feeling overwhelmed, symptoms of traumatic distress, maladaptive behavior and persistent disbelief about the loss

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Myth #1: Grief is avoidable.

- Loss is a universal, inevitable part of life.
- If you experience love (attachment), you are at risk of grief and loss. Only those who never love (attach), never grieve.
- Grief crosses all cultural and historical constructs.

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Myth #2: The best way to grieve is to move away from the pain rather than towards it

- Society encourages running away from grief.
- Feelings of pain are often seen as "bad" or inappropriate.
- Causes individuals to grieve in isolation or run away from grief using various means.
- Embracing and honoring pain is an important part of healing.
- Healing comes not just from grieving but from mourning – feeling the pain, expressing the grief and working through it.

"We are healed of a suffering only by experiencing it in the full."
Marcel Proust

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Myth #3: The grief process is predictable and orderly. There is a right way to grieve.

- Grief is messy and unpredictable.
- Individuals grieve in ways very personal and unique to them.
- There is no normal timetable or "right way" to grieve.
- Grief does not follow a prescribed "stage" format.
- Individuals should be allowed to follow their own process with no value judgements on how they "should" feel or where they "should" be.

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Myth #4: Remembering the loved one makes it harder to heal.

- Talking about the loved one and reliving memories is an effective tool for healing
- Death does not end the attachments formed by relationship.
- The relationship changes from physical to one of memory.
- Some memories are painful and need to be worked through.
- Repressing memory - good or bad, slows down the healing process.
- Repressed memories and emotions often manifest in other ways, such as illness and unhealthy behaviors.

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Myth #5: After a death of a loved one, "getting over it" or "gaining closure" is the goal.

- There is no "getting over" or "gaining closure" from the loss of a loved one.
- Life is forever changed.
- Reconciliation – integration of the loss into life in order to move forward
- New Normal
  - Full realization and acceptance of the finality of the death
  - Ability to participate in enjoyable activies
  - Sleeping/eating more normally
  - Less preoccupation with thoughts of the deceased
  - Accepting new roles caused by the death
  - Establishing new relationships
  - Look towards the future with hope

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Myth #6: Once grief is resolved or "worked through," the grieving process is finished.

- Grieving is never completely over.
- "Grief bursts" can happen at anytime…even years later.
- Although the loss won't dominate life indefinitely, it will always be an integral part of life.

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Grief Theory…An Overview

Detachment from Deceased
- Freud – early 1900's

Stage Theory
- Kubler-Ross – 1969

Phase Theory
- Bowlby and Parkes – 1970's

Tasks
- Worden – 1980s

Dual Process
- Stroebe and Schut - 1995

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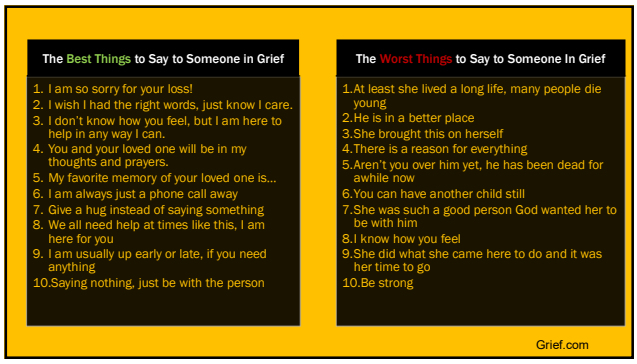
The Best Things to Say to Someone in Grief
1. I am so sorry for your loss!
2. I wish I had the right words, just know I care.
3. I don't know how you feel, but I am here to help in any way I can.
4. You and your loved one will be in my thoughts and prayers.
5. My favorite memory of your loved one is...
6. I am always just a phone call away
7. Give a hug instead of saying something
8. We all need help at times like this, I am here for you
9. I am usually up early or late, if you need anything
10.Saying nothing, just be with the person
The Worst Things to Say to Someone In Grief
1.At least she lived a long life, many people die young
2.He is in a better place
3.She brought this on herself
4.There is a reason for everything
5.Aren't you over him yet, he has been dead for awhile now
6.You can have another child still
7.She was such a good person God wanted her to be with him
8.I know how you feel
9.She did what she came here to do and it was her time to go
10.Be strong
Grief.com

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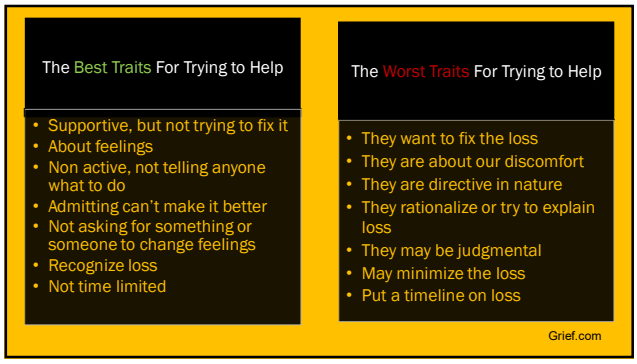
The Best Traits For Trying to Help
• Supportive, but not trying to fix it
• About feelings
• Non active, not telling anyone what to do
• Admitting can't make it better
• Not asking for something or someone to change feelings
• Recognize loss
• Not time limited
The Worst Traits For Trying to Help
• They want to fix the loss
• They are about our discomfort
• They are directive in nature
• They rationalize or try to explain loss
• They may be judgmental
• May minimize the loss
• Put a timeline on loss
Grief.com

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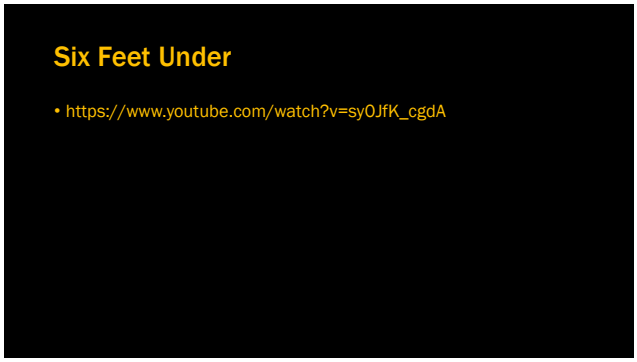
Six Feet Under
• https://www.youtube.com/watch?v=syOJfK_cgdA

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Q&A

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"His underwear was spotless."

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Reflection for the Week

What is your one takeaway from spending five weeks thinking about death and dying?

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

The true value of life is only fully revealed when it confronts death at close quarters.

Apoorve Dubey, Living Life from the Inside Out

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