

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

How are you making sense of **life and death** during the current pandemic?

1

Become a **VCU** Gerontologist

Death and Dying In the COVID-19 World
Week 2

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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Course Objective

To recognize the importance of:

- Self-determination
- The uniqueness of the individual
- The individuality of death

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COURSE INSTRUCTOR

Enid Walker Butler
Adjunct Instructor

Department of Gerontology
College of Health Professions
Virginia Commonwealth University



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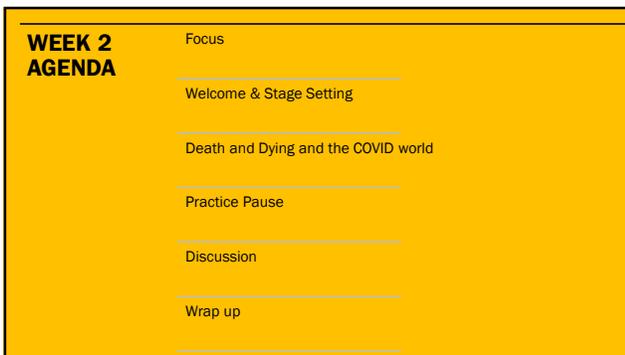
The Course

1 Week 1 Death and Dying - an Overview	2 Week 2 Death and Dying in the COVID19 World	3 Week 3 The Cultural, Spiritual and Psychosocial Aspects of EOL	4 Week 4 Models of Care and Advance Care Planning	5 Week 5 Loss and Grief
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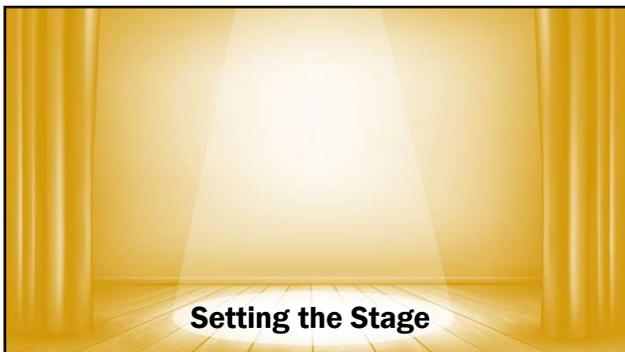
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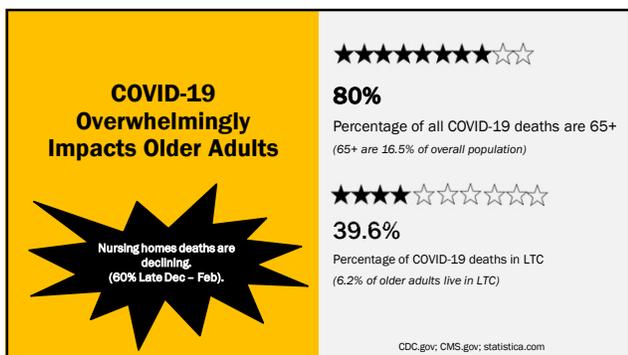
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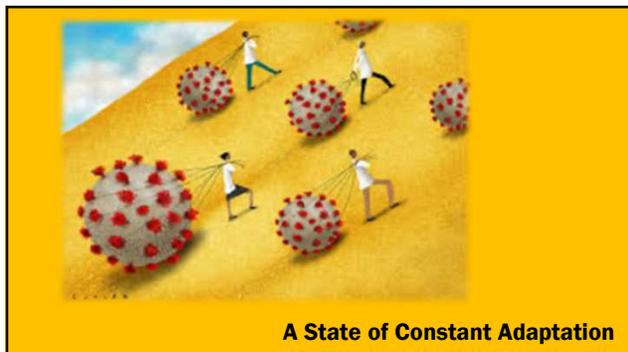
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The Good Death

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	Death in 1900	Death in 2000	Death in 2020 Impact of COVID
Life Expectancy:	47.3 years old	78.9 years old (2019)	77.5 years old -1.4 Years
Cause of Death:	Infectious Disease Smallpox, influenza, scarlet fever, pneumonia	Degenerative/Chronic disease Heart disease, cancer, stroke, lung disease, dementia	Heart Disease, Cancer COVID-19
Trajectory:	Rapid, brief (days, weeks)	Slow decline (months, years)	Rapid, brief (days, weeks)
Location:	80% at home Only poor died in institutions	80% in institutions, i.e., hospitals, nursing homes	95% in hospitals or long term care
Caregivers:	Family Members	Paid Professionals	Paid Professionals (Family visits limited)
Death Encounter:	Intimate, Close, Participant	Removed, Sanitized, Observer	Isolated, Limited
Role of Physician:	Comforter, Consoler	"Curer-er," Miracle Worker	Crisis Management

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The Notion of A "Good Death"

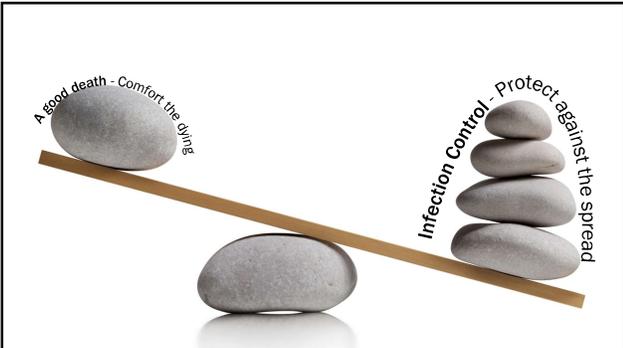
Preferences for the Dying Process Treatment Preferences Symptom Control	Treatment plan reflects life values, autonomy over decision making/treatment decisions, affairs in order, no suffering
Spirituality/Religiosity Emotional Well Being Dignity	Exploration of spirituality/religious beliefs, meaning of death, emotional and psychological support, independence
Family Life Completion	Life review/reflection, saying goodbye/closure, family support and presence, family prepared for death, memorializing in appropriate cultural/spiritual mores

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COVID-19 impacts the dying experience for both the COVID-19 and the non-COVID-19 individual and their loved ones



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COVID-19 Impact on "Good Death"

<p>Preferences for the Dying Process Treatment Preferences Symptom Control</p> <p>Affairs may not be in order Decisions being made under duress, May lack the ability to express needs, POA directs care remotely</p>	<p>Spirituality/Religiosity Emotional Well Being Dignity</p> <p>Either limited or no visits by family allowed, Lack of staff to spend time on psycho-social needs, Limited accessibility by outside HCP such as hospice chaplains, MSWs, bereavement</p>	<p>Family Life Completion</p> <p>Lack of time to prepare and process Loved ones not allowed at bedside at EOL Goodbyes often virtual or outside a window Social distancing requirement impacts memorializing</p>
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Hospice Care

Hospice enrollments are up – families want their loved ones to die at home.

Existing hospice patients are limiting in-home visits due to fear of exposure (primarily clinical staff and aides allowed.)

Long term care and nursing facilities limit visits from hospice staff, most requiring proof of negative COVID-19 test for entry.

PPE interferes with therapeutic relationships

High use of technology-based visits

Volunteer visits suspended indefinitely

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Advance Care Planning

COVID-19 dynamics create greater need than ever

ACP providers developing COVID-19 specific materials

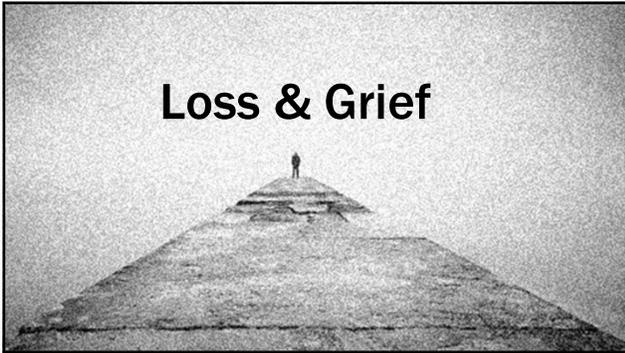
Positioned as way to help reduce virus uncertainty

Particularly important with patients dealing with chronic, life-limiting diseases

Ineffective to focus on code status without understanding goals and values



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Our Assumptive World

What we believe to be true that makes us feel safe and secure

Assumptions that ground us in a sense of reality, purpose and meaning

Belief in self-efficacy, a measure of control and the future is somewhat predictable

(Menziez, Neimeyer, Menziez, 2020)

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The Shattering of Our Assumptive World

COVID-19 has shattered our assumptive world

- How we die
- How we memorialize and mourn
- Sense of safety
- Economic uncertainty
- Societal value of lives of others (Ageism)
- Social Distancing/Masks (Isolation)
- Division over the role of government
- Division over information/science

Includes Both death and non-death losses

(Menziez, Neimeyer, Menziez, 2020)

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Tsunami of Loss and Grief

Traumatic Loss	Disenfranchised Grief	Complicated Grief
<ul style="list-style-type: none"> • An event perceived to be unavoidable that threatens injury or death to self or others. • Clicks psyche into "survival mode." • Loss accompanies the threat but may be a non-death loss 	<ul style="list-style-type: none"> • Grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned" 	<ul style="list-style-type: none"> • Complicated grief involves: <ul style="list-style-type: none"> • prolonged unresolved feelings • sense of feeling overwhelmed • Symptoms of traumatic distress • Maladaptive behavior • Persistent disbelief about the loss

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Death-Related Ageism

A society is measured by how it cares for its "older" citizens. (WHO, 2019)

"The public discourse during COVID-19 misrepresents and devalues older adults." (Fraser et al., 2020)

Heightened ageist attitudes in the media portray COVID-19 as an older adult issue.

Emphasis needs to be placed on the societal loss that occurs with the death of an elder – wisdom and knowledge, contribution, family structure, the economy – assets, workforce, volunteerism.

Collective, intergenerational commitment is needed to increase support and interaction/connection of older adults.

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The Impact of Isolation

In general, older adults who are isolated have an increased risk of overall health decline and morbidity.

No comprehensive count of COVID 19 isolation-related deaths but evidence reveals a mounting impact on health conditions and death.

Despite concerted efforts towards socialization by LTC staff, health professionals are seeing an increase in depression, cognitive decline and health conditions such as weight loss, high blood pressure, stroke in addition to premature death.

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Death Anxiety

Death Anxiety: Negative attitudes and emotions towards death and dying

The COVID-19 environment has increased overall death anxiety due to nearly constant awareness and presence of the possibility of death.

Data on mental health impact still emerging, although anecdotal evidence infers a major impact on mental health.

Mitigating behaviors

- Suppression – Turning off the news
- Denial – "I'm not in a high-risk category" "It's really just like the flu"
- Prevention – Cleaning surfaces, quarantining/isolating

(Menzies, Neimeyer, Menzies, 2020)

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Meeting the Needs

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Connecting at End-of-Life

Two-way communication important

Reminders of love and support

PATIENT <-> FAMILY

Hospitals and LTC now allowing limited visitation for residents at EOL

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Connection - Ideas

- Letters, cards, artwork from family
- Calls and cards from hospice volunteers
- Video, photo & audio messages
- "Real time" video or audio
- Zoom-type "gathering" with family & friends
- Visits in outdoor spaces of facility or outside the window

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Funerals

All cultures and civilizations attend to the proper care of their dead.

Convey our belief systems, ideas and emotions surrounding the death of a loved one.

Laden with history and symbolism.

Frame the meaning of death and shape the response to loss and change.

Are central to moving through grief to new life.

The disruption of these practices disrupts the grief process.

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“Replicate As Close As Possible”

Funeral homes balancing state COVID-19 mandates with needs of families to memorialize according to their traditions.

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Memorializing

Graveside with traditional event "later"	Live-Stream - Funeral home website & FB Live	Drive-by or rolling funeral
Notes, photos, special items for cremation or burial	Candlelight vigil at home of deceased	Virtual Zoom-type events <ul style="list-style-type: none"> • Reception for family and mourners • Story telling event for family and those close to the loved one
Encourage creativity <ul style="list-style-type: none"> • Home altar • Planting a tree • Picking up a hobby or skill of the loved one • Cooking event of special recipes 		

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<h2>Bereavement</h2>	<p>Increased demand and pressure on chaplains and bereavement professionals</p> <p>Support needed for both the death AND COVID-19 related isolation and anxiety</p> <p>Difficult to deliver bereavement interventions and follow bereaved clients virtually</p>
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<h2 style="margin: 0;">Bereavement Support</h2>	<p>Virtual support groups</p> <p>Regular calls, check-ins</p> <p>Notes – handwritten, texts</p> <p>“Real-time” virtual visits (parallel play)</p> <p>Exercise/Movement - virtually or in person</p> <p>Check in on special dates such as birthdays, etc.</p>
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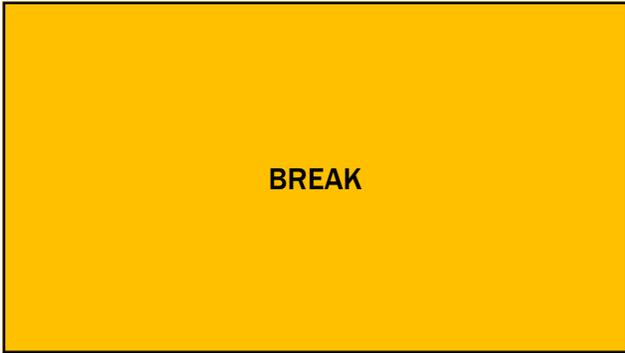
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 <p style="text-align: center; font-weight: bold; font-size: 1.2em;">T*A*P*S</p> <p style="font-size: 0.8em;">THESEAL, AMERICAN SOCIETY OF HOSPICE AND PALLIATIVE CARE</p> <p style="font-size: 0.8em;"> Dr. Charles Corr Dr. Kenneth Doka Dr. Robert Nelmeier Dr. Therese Rando Dr. William Worden </p>	<p>COMPLICATED GRIEF INITIATIVE</p> <p>Call to Biden for comprehensive response to pandemic grief</p> <ul style="list-style-type: none"> Second Potential Pandemic Insufficient Resources to Address Est. 500 people suffering from complicated grief just from COVID deaths. <p>Request:</p> <p>Concerted multidisciplinary effort</p> <p>Training of professionals</p> <p>Public education</p> <p>Research</p> <p>Hospice bereavement</p>
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<h2 style="margin: 0;">Interventions in your workplace</h2> <p style="margin-top: 20px;">Interactive Exercise</p>

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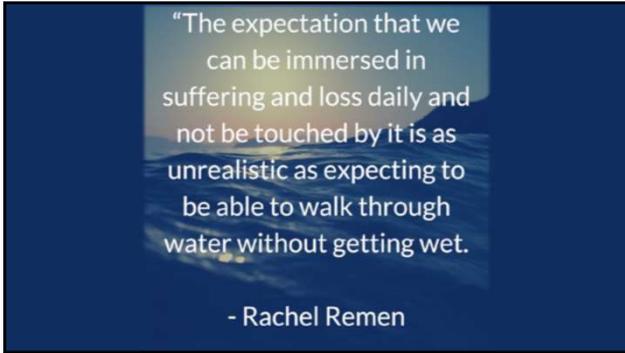
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The Impact	<p>"Scared" - Worried about self and family Tension over commitment to professional role vs. personal safety Constant concern about spread Changing protocols Ethical considerations about patient care Not able to deliver "a good death" - <i>Often conduit for heart-wrenching farewell messages</i> Isolation High Turnover; staff shortages Daily usage of PPE Witnessing client decline due to isolation</p>
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Self-Care is Not Optional

Ethical responsibility for self-care	Top-down support is critical
One size does not fit all	Benefits: <ul style="list-style-type: none">• Focus on present moment• Create new meaning• Reminder of what is important• Reduced anxiety, encourages sense of well-being• Predictable sense of structure

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Self-Care is Soul-Care

Maintain structure – routine brings a degree of normalcy and a sense of control.

Connect, connect, connect - even if it's virtually.

Sustain or start healthy habits – exercise, nutrition, sleep

Ask for help – don't "suck it up" until you are in trouble.



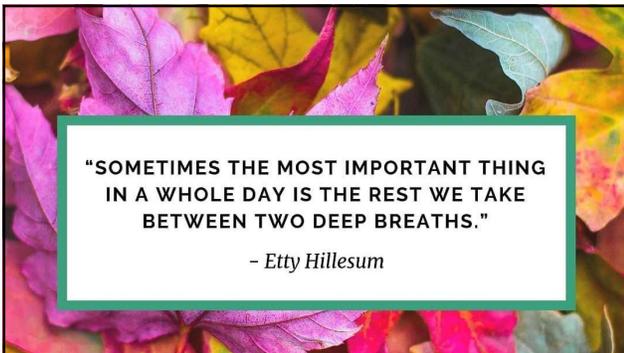
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Self-Care is Soul-Care

Stuffing strong emotions will only make things worse.
Remember what you love about your job/life.
Tend to your spirituality.
LAUGH. A Lot.



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Hospice Agency: Case Study

- Objective: Holistic, multi-faceted provide support for staff
- Goals: Communication, appreciation, community, self-care
- "COVID Survival Kit"
- Handwritten notes (by volunteer)
- "Press the Pause Button" - Self-care rituals
- Team "huddle" calls increased to twice daily
- Handmade masks given twice; Goodie bag from volunteer
- Box lunches - delivered in the field, picked up at office
- IDT Meeting - Time to process, messages of encouragement
- Work-sponsored exercise contest
- Zoom Christmas party



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Exercise

What are you doing for self-care?
What is one change, even if it's a small one,
that you can make towards self-care?

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Reflection for the Week

What lessons have you learned from the pandemic that you want to bring with you both professionally and personally?

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

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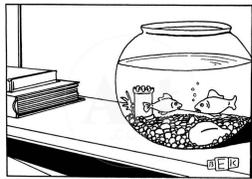
(804) 828-1565

agingstudies@vcu.edu

<https://gerontology.chp.vcu.edu/>

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Let's keep this one for the final session where we cover funerals.



"You already made arrangements to be flushed down the toilet."
