

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.

# YOUR INSTRUCTORS

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<https://tinyurl.com/death-and-dying>

# *The Good Death*

## *Module 1*

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*March 13, 2023*



FAIRFAX COUNTY DEPARTMENT OF  
**FAMILY SERVICES**  
ADULT AND AGING



LONGEVITY  
PROJECT  
for a greater Richmond



# 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.

# THE SERIES

1

Week 1

Death and Dying:  
The Good Death

*Session 1: An  
Overview*

*Session 2: Models of  
Care*

2

Week 2

The Trifecta: Grief  
Loss and Trauma

*Session 1: An Overview*

*Session 2: Practical  
Application*

3

Week 3

The Toolbox

4

Week 4

Leading the Way  
(For Supervisors)



# Death and Dying – the Good Death



## ***COURSE OBJECTIVES***

To understand the dynamics of death in the US and what the research says about "The Good Death."

To understand the psychosocial and spiritual factors of the dying process and how that impacts us as providers of care.

To develop a working knowledge of EOL care models.

To understand the tools available for EOL decision-making.



# SKIMMING THE SURFACE





REMINDE YOURSELF  
THAT IT'S OKAY  
NOT TO BE  
PERFECT

[quotes4sharing.com](http://quotes4sharing.com)







# Major Tenets

We live in a death phobic society.

Individuals with terminal illness are still living human beings.

Dying is *very* individual.

Everyone in the equation experiences the death differently.

The death experience is highly *nuanced*, rarely black and white.

**There is not one universally right way to die.**



# Death Averse Society

"Of all of our human experiences, none is more overwhelming in its implications than death." *(Despelder & Strickland, 2011)*

Western cultures often see death as an enemy to be defeated with the weapons of medical technology and modern medicine.

This type of death aversion "estranges us from an integral aspect of human life."

*(Despelder & Strickland, 2011)*

Research shows the more we talk about death the more comfortable we are with it.

It's important that we get comfortable with the *uncomfortable*.

# Ageism and End of Life (EOL)

Elders experience ageism and discrimination through societal attitudes, media portrayal and employment, among others.

Death is no exception.

Approximately 75% of all deaths occur past the age of 65.

## This connection to death:

- Drives fears
- Is reminder of individual mortality
- Often drives psychological distancing from older adults and resulting ageism.

**As providers, we need to look at our own ageist attitudes towards older adults and death.**



# Words Matter

A background image showing two women in conversation. On the left, a woman with dark curly hair is seen from the back, wearing a light-colored blazer. On the right, an older woman with short white hair and glasses is smiling and gesturing with her right hand. She is wearing a dark green shirt with white polka dots. The background is a blurred stone wall.

**PROVIDE YOUR SYNONYM(S) FOR "DEATH"**

# Words Matter

Euphemisms for death can be both useful and detrimental.

- Protective quality, modulate emotion
- Reflect belief system i.e. "crossed over"
- May keep an individual in denial
- May create a false picture of patient status

Using euphemisms can cause issues in the health care setting.

Important that healthcare providers use clear, direct language.



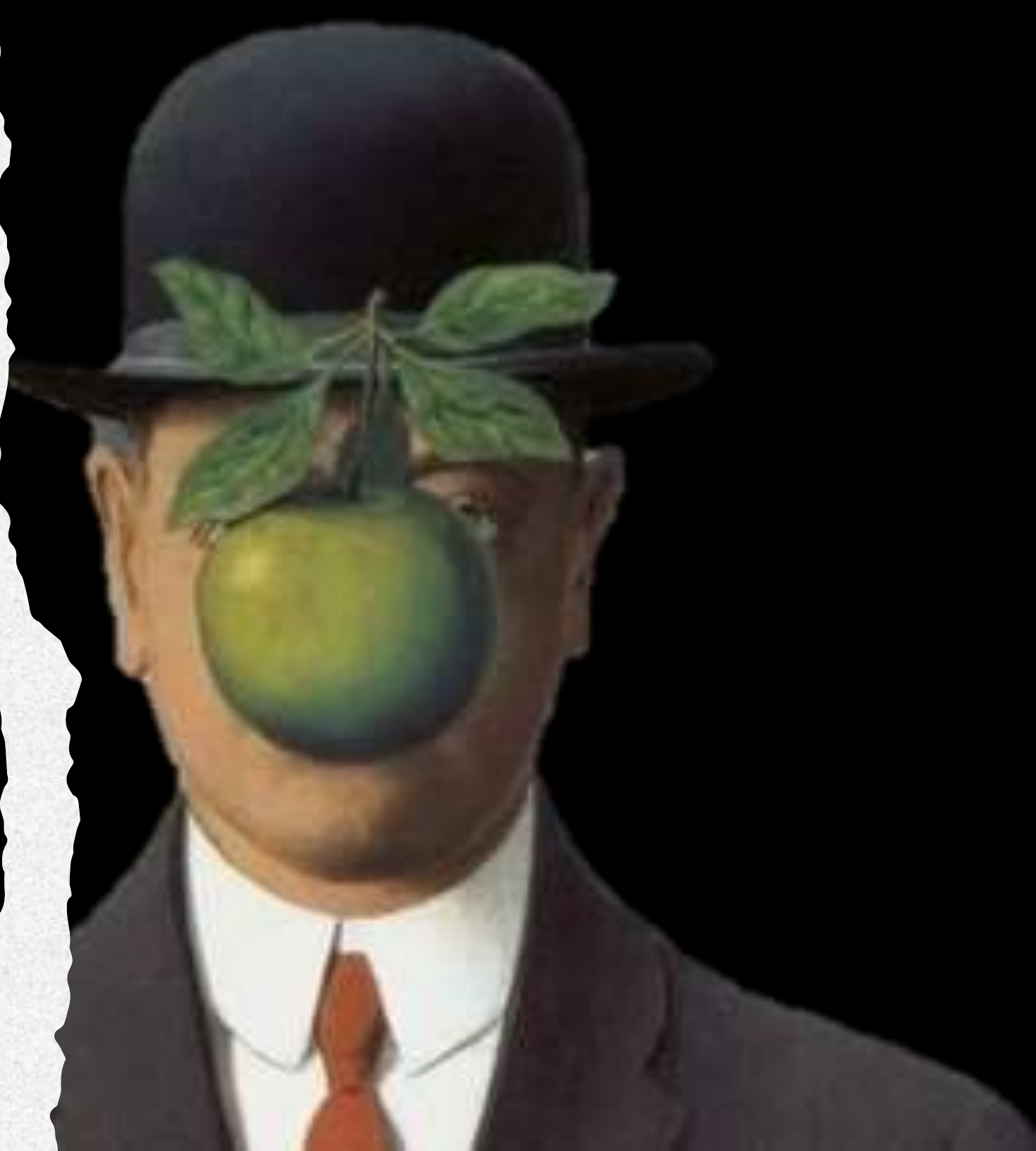


The unexamined life is not worth living.

*Socrates*

The unexamined death is not worth dying.

*Anonymous*







# POLL

1. Have you given serious thought or **"examined" your own death?**
2. Do you avoid even thinking about it?
  - ☐ Yes, I avoid thinking about it.
  - ☐ No, I don't avoid thinking about it.
  - ☐ I probably avoid thinking about it but want to believe I remain open.

They are still alive and often have “unfinished business” they want and need to address.

We need to listen actively to them in order to identify with them their tasks and needs so that we can be effective providers of care.

They have much to teach us about our shared humanity and the final stages of life with all of **it's** anxieties, fears and hopes.

(Kübler-Ross, E. 1969)

Why is it  
important  
**to “pay  
attention”**  
to the  
dying?



# 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.**



What is death?



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

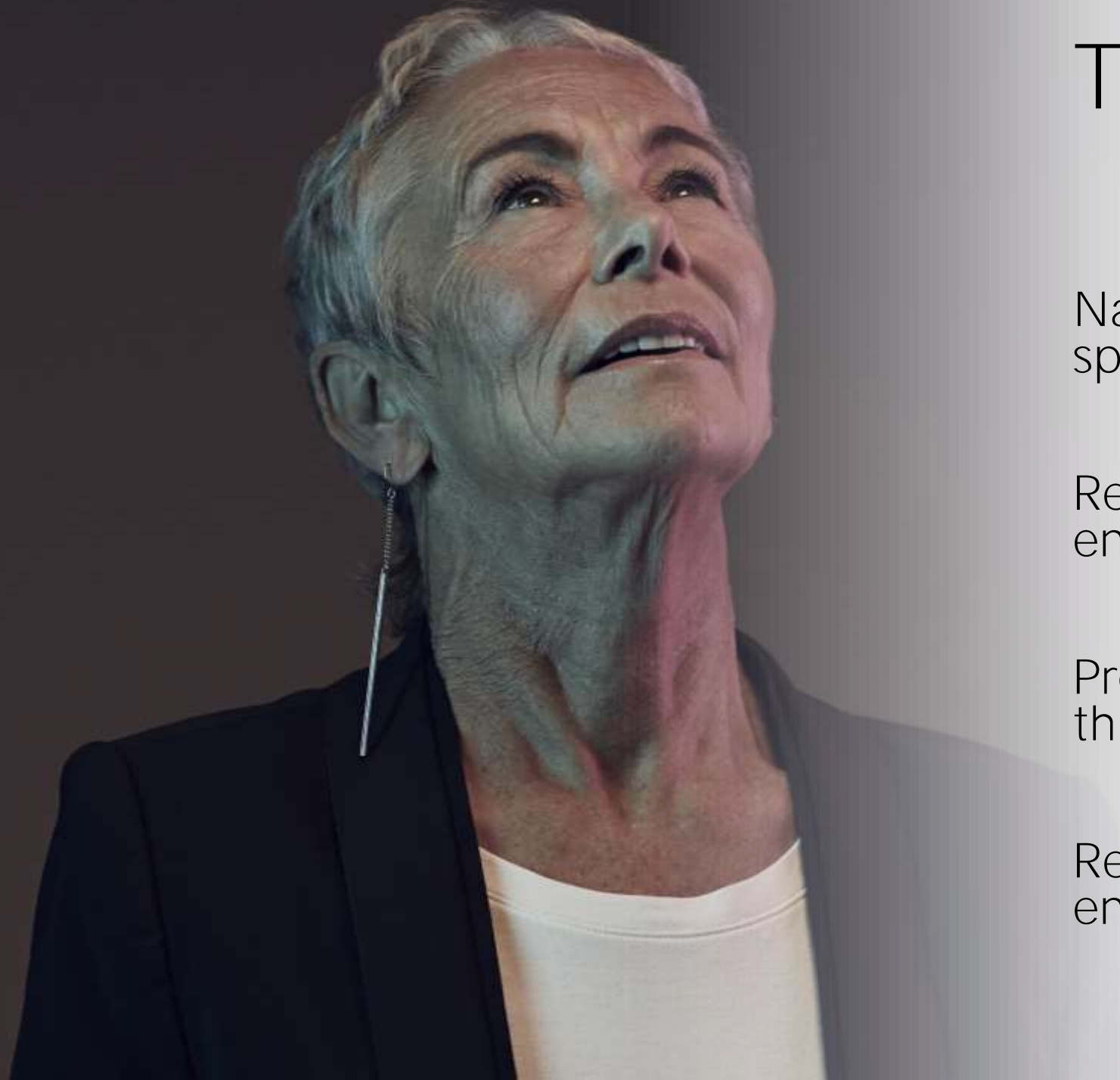


# Death Is Multi-dimensional

The Physical: The natural process of shutting down

The Psychosocial/Spiritual:  
**The "spirit" releasing the**  
natural body.





# The Process

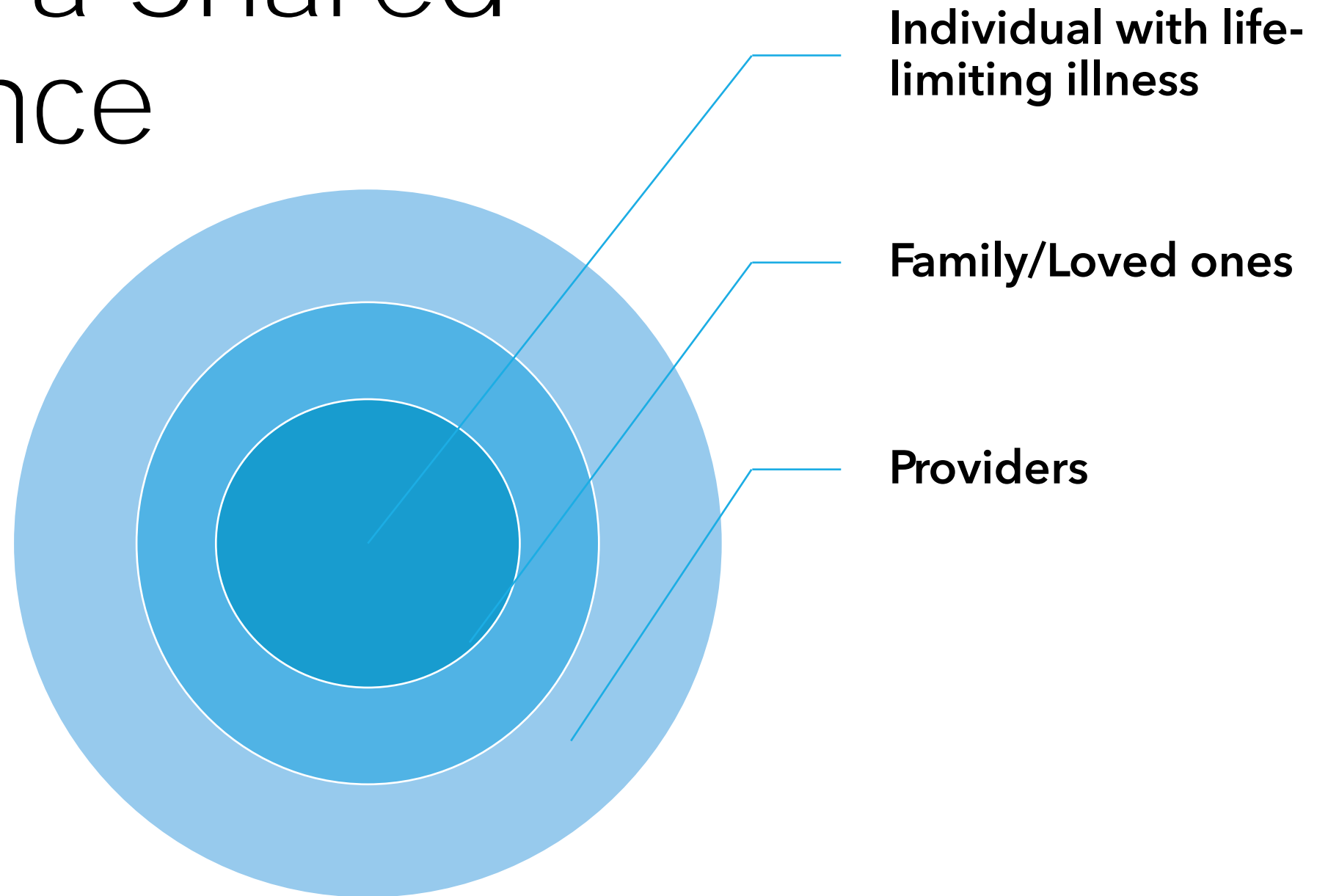
Natural process of emotional, spiritual, mental release

Release of the body and environmental attachments

Prepares spirit to move from this existence to the next

Requires support and encouragement

# Death is a Shared Experience







# POLL

How do you see your role as a **stakeholder** in a client's end of life experience?

- 1) I don't think I am a stakeholder
- 2) I do what I can to support a client at end of life but don't think it really makes a difference
- 3) I am instrumental in the end of life process for my clients.

*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.*



Cultural

Biological

Spiritual

Psychosocial





A close-up photograph of a woman with her eyes closed and a joyful smile. Her face and hair are covered in a thick layer of vibrant, multi-colored powder (red, yellow, green, blue, and purple). She is wearing a purple garment with intricate gold embroidery. The background is a soft, out-of-focus blur of similar colors, suggesting a festive or cultural celebration. The text "The Role of Culture" is overlaid in the center in a white, serif font.

# The Role of Culture



*"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*





# 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.

(Corr & Corr, 2013, DeSpelder & Strickland, 2011)

Culture is the lens through  
which we navigate our life...  
and our death.



# 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



# 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.

# 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/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.*

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*



# The Good Death

A landscape photograph featuring a dirt road that curves through a golden field towards a distant horizon. A faint rainbow is visible in the sky above the road. The sky is filled with soft, colorful clouds in shades of blue, purple, and orange, suggesting a sunset or sunrise. The overall mood is contemplative and serene.

A good death?

How would you define  
a good life?

## DID YOU KNOW?

*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.



According to the  
Institute of Medicine, a  
“good death” is:

“Free from avoidable distress and suffering for the patient family and caregivers in general accord with the patient’s and family’s wishes and reasonably consistent with clinical, cultural and ethical standards.”

(Meier, Gallegos, Montross-Thomas, 2015)

# Psychological Evaluative Process

Dying individuals go through a unique psychosocial process to the extent that their emotional, cognitive, physical abilities allow.

Opportunity for personal growth and even joy.

Consistent with empirical studies of “a good death” and theories such as:

*Sudnow: Four Types of Death*

*Tornstam: Gerotranscendence*

*Corr: Task Model*

# 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***



# Pain-Free Status

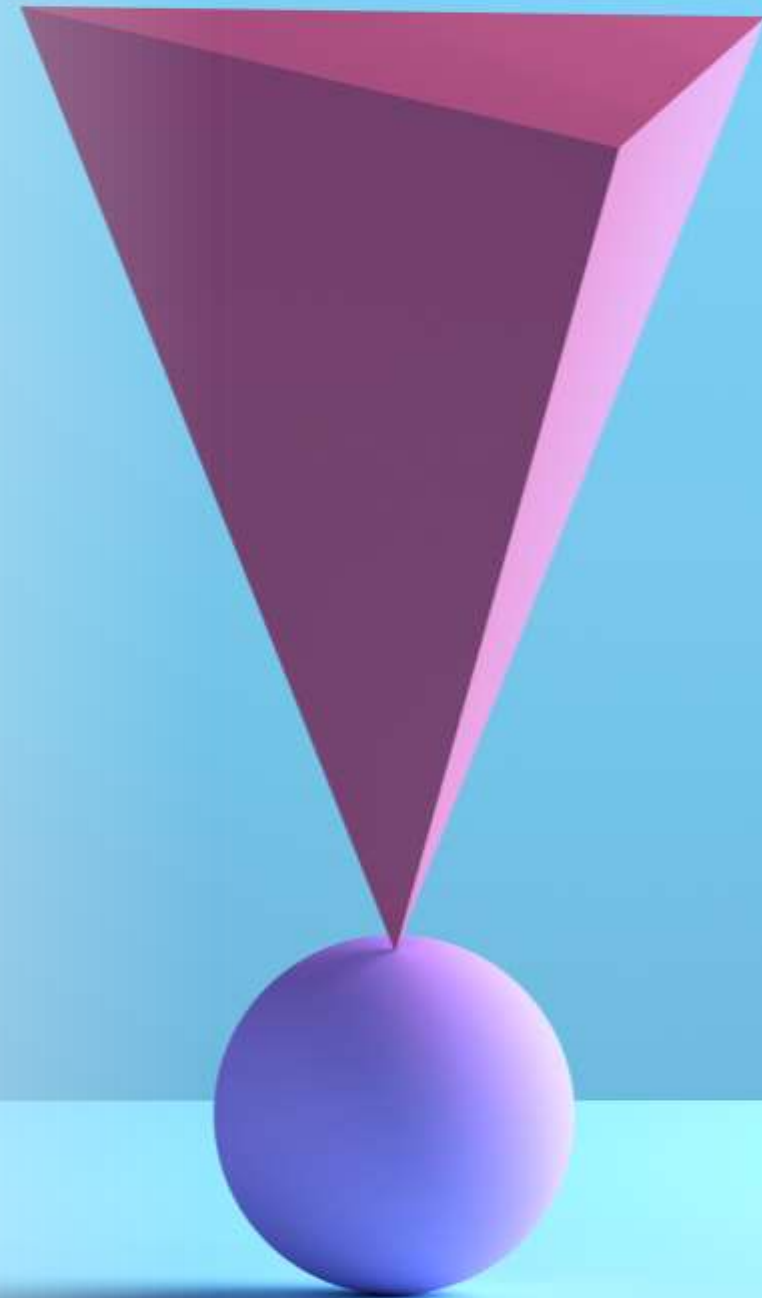
## *Feeling No Pain*

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.



# Life Completion *Looking Back*

Developmental task of “Maturity” or “Completion,” inner sense of wholeness.

Reframing of past conflicts into new meaning (Often, where regrets are expressed.)

Attained by introspection and self-reflection that facilitates reconciling **one’s life choices and achievement.**

Closure with loved ones – goodbyes, reconciliation/repair of relationships



# Emotional Well-being

## *Peace of Mind*

Emotionally and psychologically supported

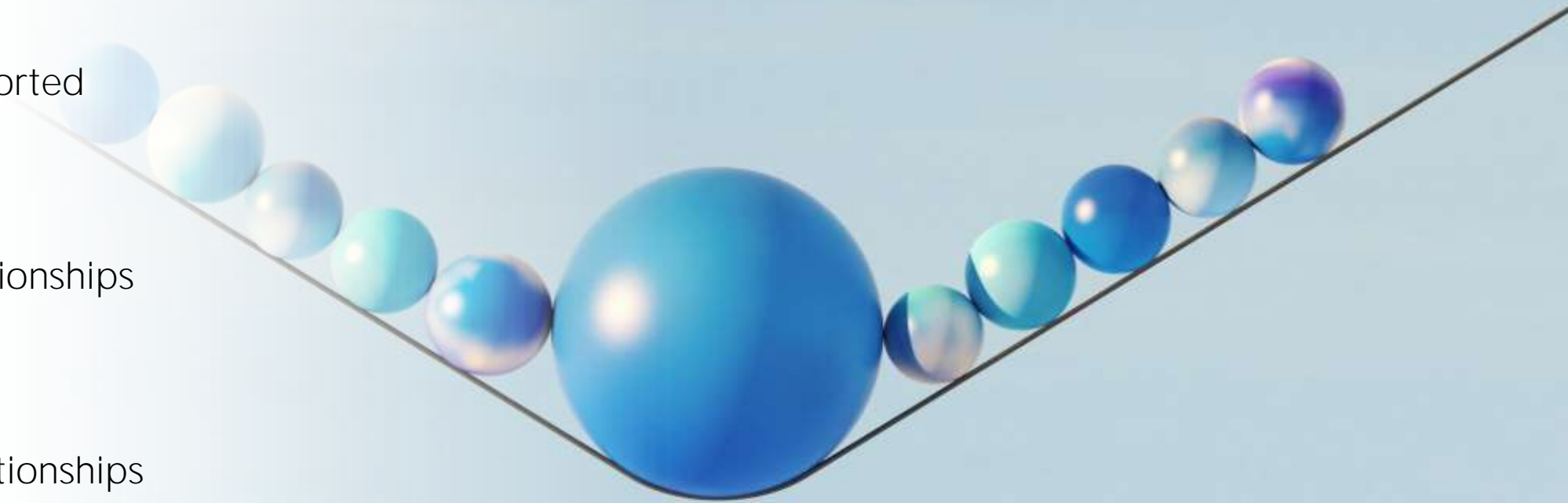
Finding & maintaining inner peace

Maintaining and improving close relationships

Addressing fear of abandonment.

May narrow focus to most valued relationships and activities.

Ability to explore meaning of death



(Corr & Corr, 2013, DeSpelder & Strickland, 2011, Meier et al., 2015)



# Dignity

## *A Sense of Worth*

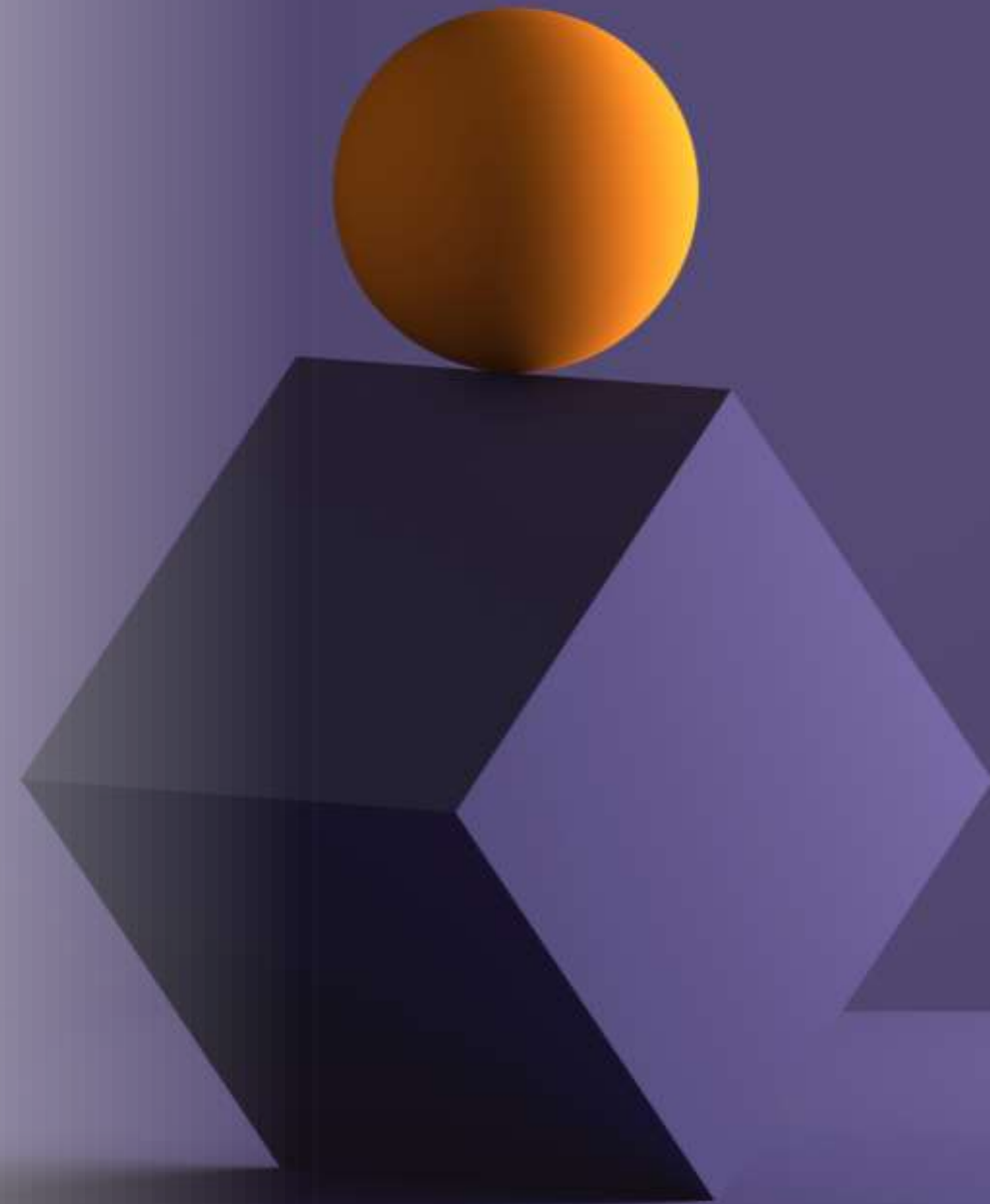
Desire to maintain personal dignity “disease process” or “dying individual.”

Ageism and age-related losses devalue perception of worth.

Life-threatening illness feelings of loss, lack of value and self-worth.

Loss of social and familial roles, loss of future goals and plans.

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).



# Quality of Life

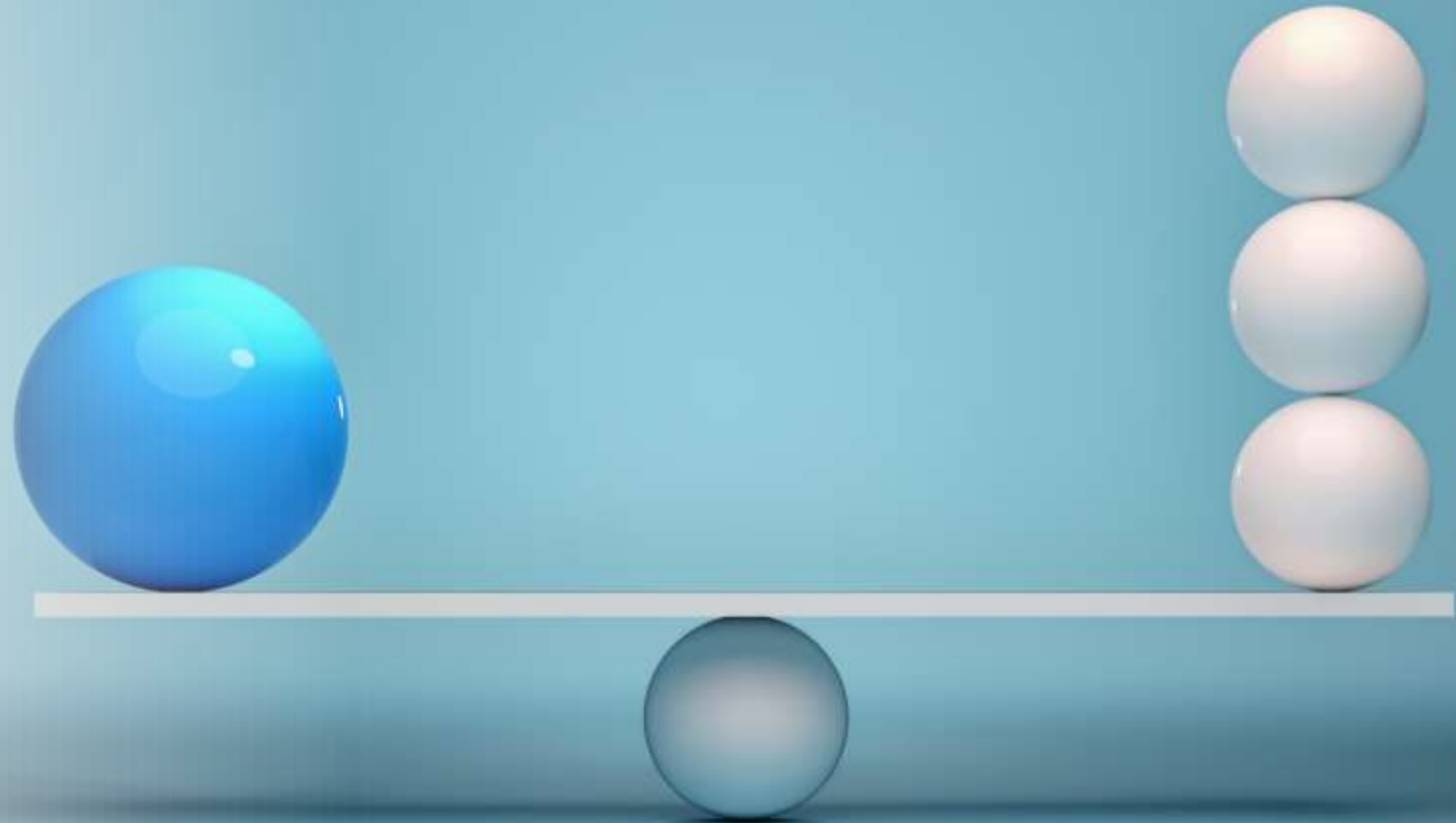
## *A Life Worth Living*

“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 disease progresses, illness-related losses and dependence on others increase*





# 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.*





# 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

## Spirituality

- Ways individuals search for and define meaning and experience connectedness.
- Connectedness encompasses: idea of God or a higher power, self, others, nature

## Religion

- 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.



# Spirituality & Religion

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Source of transforming hopelessness into hope, meaning and gratitude.

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Significant source of coping, strength, comfort and community

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Assurance of being loved

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

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

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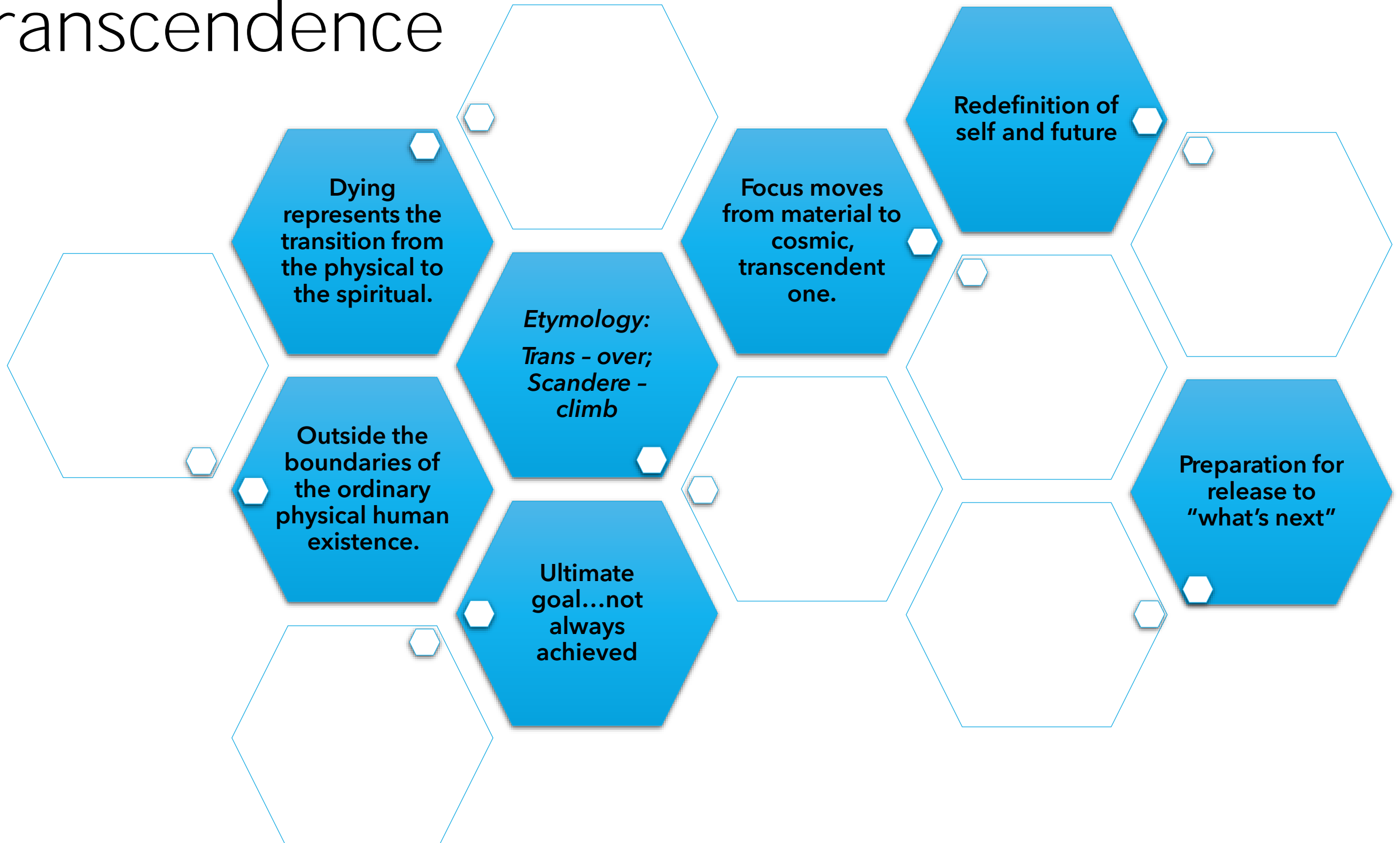
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Individual's spiritual struggle and re-examination of belief systems can look like unbelief

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# Transcendence



“The tricky part of illness is that, as you go through it, your values are constantly changing.... You may decide you want to spend your time working as a neurosurgeon, but two months later, you may want to learn to play the saxophone or devote yourself to the church. Death may be a one-time event, but living with terminal illness is a process.”

— Paul Kalanithi, *When Breath Becomes Air*





# Near 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.

*(Corr & Corr, 2013, DeSpelder & Strickland, 2011, Giver, 2022)*



A large, dark-colored key with a circular head and a long, straight shaft lies diagonally across a light blue wooden surface. A small, rectangular white tag is attached to the key's head with a metal ring. The tag has the word "Takeaway" written on it in a dark blue, cursive-style font. A smaller, more ornate key is visible in the background, partially obscured by the main key's shaft.

Takeaway





# References

Byock, I. (2014). *The four things that matter most: A book about living*. Atria Books.

Clarkson, B., & Lovvorn, M. L. (2014). *The heart of hospice: Core competencies for reclaiming the mystery*. Lulu Publishing.

Corr, C. A., Corr, D. M., & Doka, K. J. (2019). *Death & Dying, Life & Living*. Cengage.

DASS, R. A. M. (2022). *Walking each other home: Conversations on loving and dying*. SOUNDS TRUE.

Garber, J. (2022, February 7). *The medicalization of death: What does it mean and what can we do about it?* Lown Institute. Retrieved February 25, 2023, from <https://lowninstitute.org/how-death-became-medicalized-and-what-we-can-do-about-it/>

Givler, A., Bhatt, H., & Maani-Fogelman, P. A. (1970, January 1). *The importance of cultural competence in pain and palliative care*. Semantic Scholar. Retrieved January 22, 2023, from <https://www.semanticscholar.org/paper/The-Importance-Of-Cultural-Competence-in-Pain-and-Givler-Bhatt/0c05579f15ef83173bad59504e58d199b39c3682>

Hoofe, C. (2020, April 28). *Does using battle language around illness mean we suffer more?* Marie Curie. Retrieved February 25, 2023, from <https://www.mariecurie.org.uk/talkabout/articles/does-using-militaristic-language-around-illness-mean-we-suffer-more/274102>

Houska, A., & Loučka, M. (2019). Patients' autonomy at the end of Life: A Critical review. *Journal of Pain and Symptom Management*, 57(4), 835–845. <https://doi.org/10.1016/j.jpainsymman.2018.12.339>

Kubler-Ross, E. (1969). *On death and dying*. MacMillan Paperbacks Edition.

Marks, A., & Lucille Marchand. (2015, October). *Fast facts and concepts #118 near death awareness*. Retrieved January 22, 2023, from <https://www.mypcnow.org/wp-content/uploads/2019/02/FF-118-Near-Death-aware.-3rd-Ed.pdf>

Meagher, D. K., & Balk, D. E. (2017). *Handbook of Thanatology: The essential body of knowledge for the study of death, dying, and bereavement*. Routledge.

Meier, E. A., Gallegos, J. V., Thomas, L. P., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature Review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, 24(4), 261–271. <https://doi.org/10.1016/j.jagp.2016.01.135>

Murphy, S. L., Kochanek, K. D., Xu, J., & Arias, E. (2021, December). *Mortality in the United States, 2020 - centers for disease control and ...* Retrieved January 22, 2023, from <https://www.cdc.gov/nchs/data/databriefs/db427.pdf>

PA;, G. A. B. H. M.-F. (n.d.). *The importance of cultural competence in pain and palliative care*. National Center for Biotechnology Information. Retrieved February 25, 2023, from <https://pubmed.ncbi.nlm.nih.gov/29630206/>

Passel, J. S. (2020, May 30). *U.S. population projections: 2005-2050*. Pew Research Center's Social & Demographic Trends Project. Retrieved February 25, 2023, from <https://www.pewresearch.org/social-trends/2008/02/11/us-population-projections-2005-2050/>

Searight, H. R., & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physicians*, 71, 515–522.

Span, P. (2014, April 11). *Wounded by the language of war*. The New York Times. Retrieved February 25, 2023, from <https://archive.nytimes.com/newoldage.blogs.nytimes.com/2014/04/11/wounded-by-the-language-of-war/>

Spelder, L. A., & Strickland, A. L. (2011). *The Last Dance*. McGraw-Hill Companies1.

U.S. Census Bureau quickfacts: United States. (n.d.). Retrieved February 25, 2023, from <https://www.census.gov/quickfacts/US>