

PLEASE TAKE A
MOMENT TO
PROVIDE US
WITH YOUR
ANSWER TO
THE
FOLLOWING
QUESTION

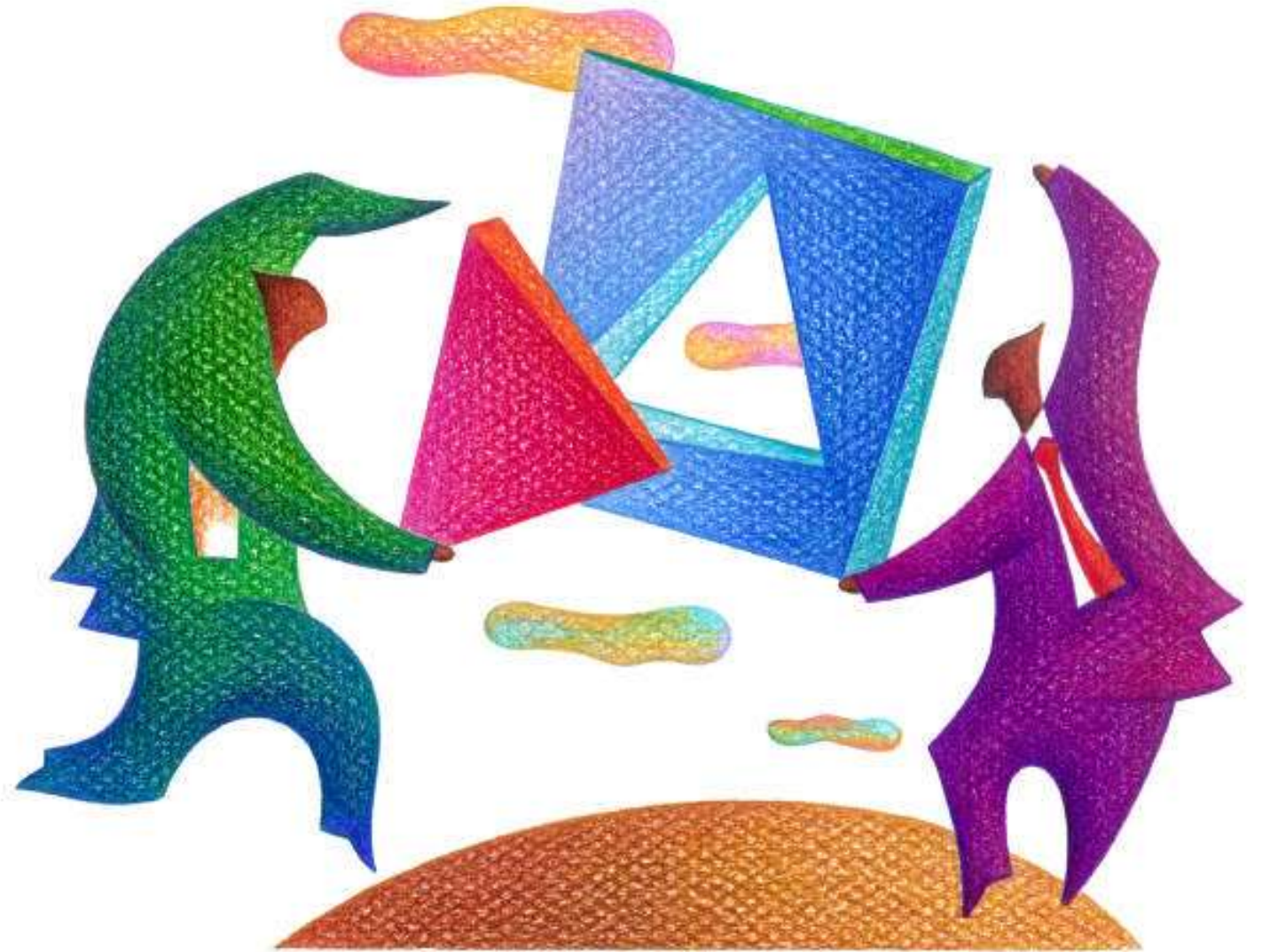
*(Use the Q&A
tab to share
your response,
please)*

**If you could write the title
of your obituary, what
would it be?**

The Good Death – Models of Care

*Module 2
March 16, 2023*

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FAIRFAX COUNTY DEPARTMENT OF
FAMILY SERVICES
ADULT AND AGING



LONGEVITY
PROJECT
for a greater Richmond

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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

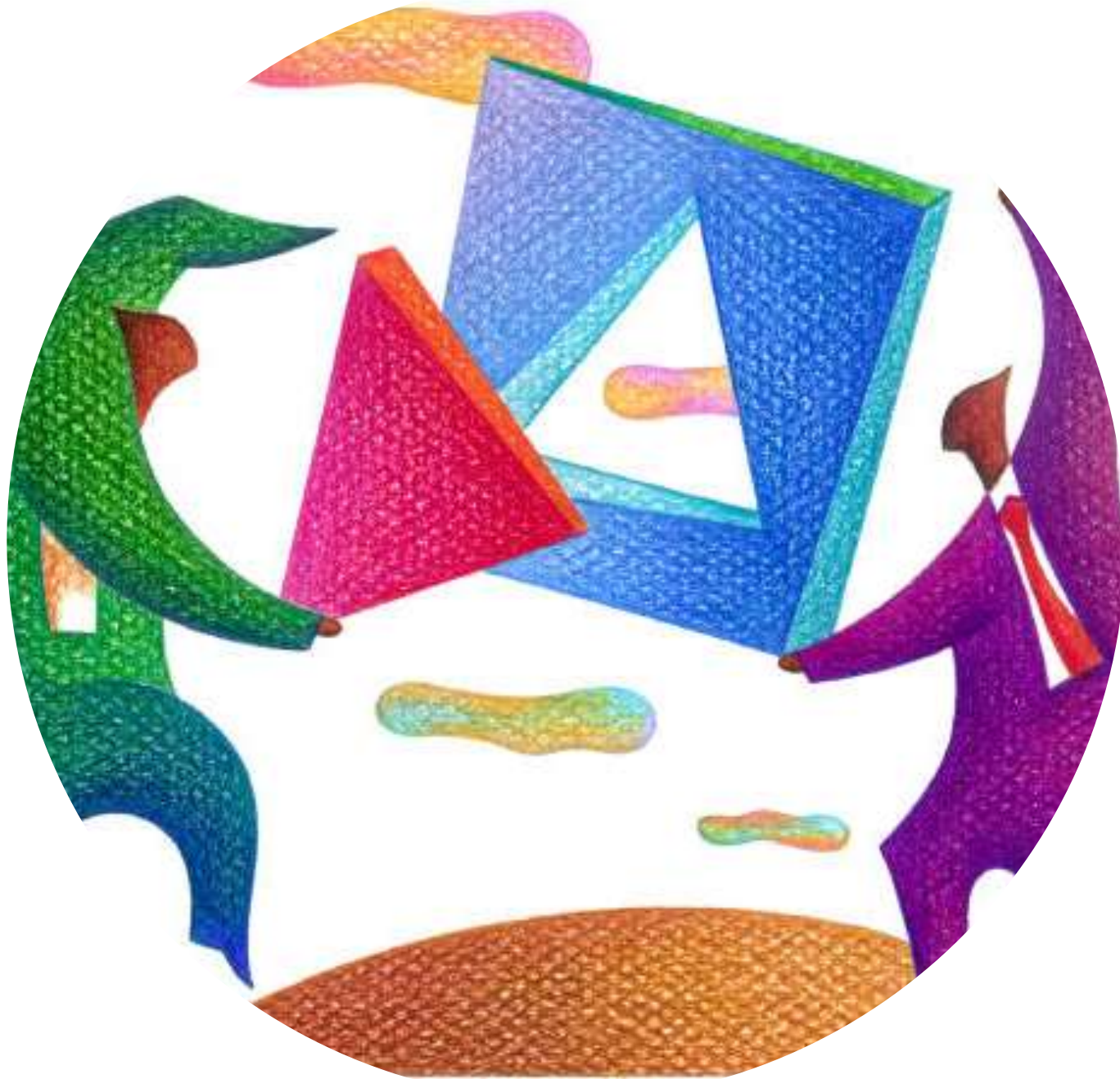
Week 3

The Toolbox

4

Week 4

Leading the Way
(For Supervisors)

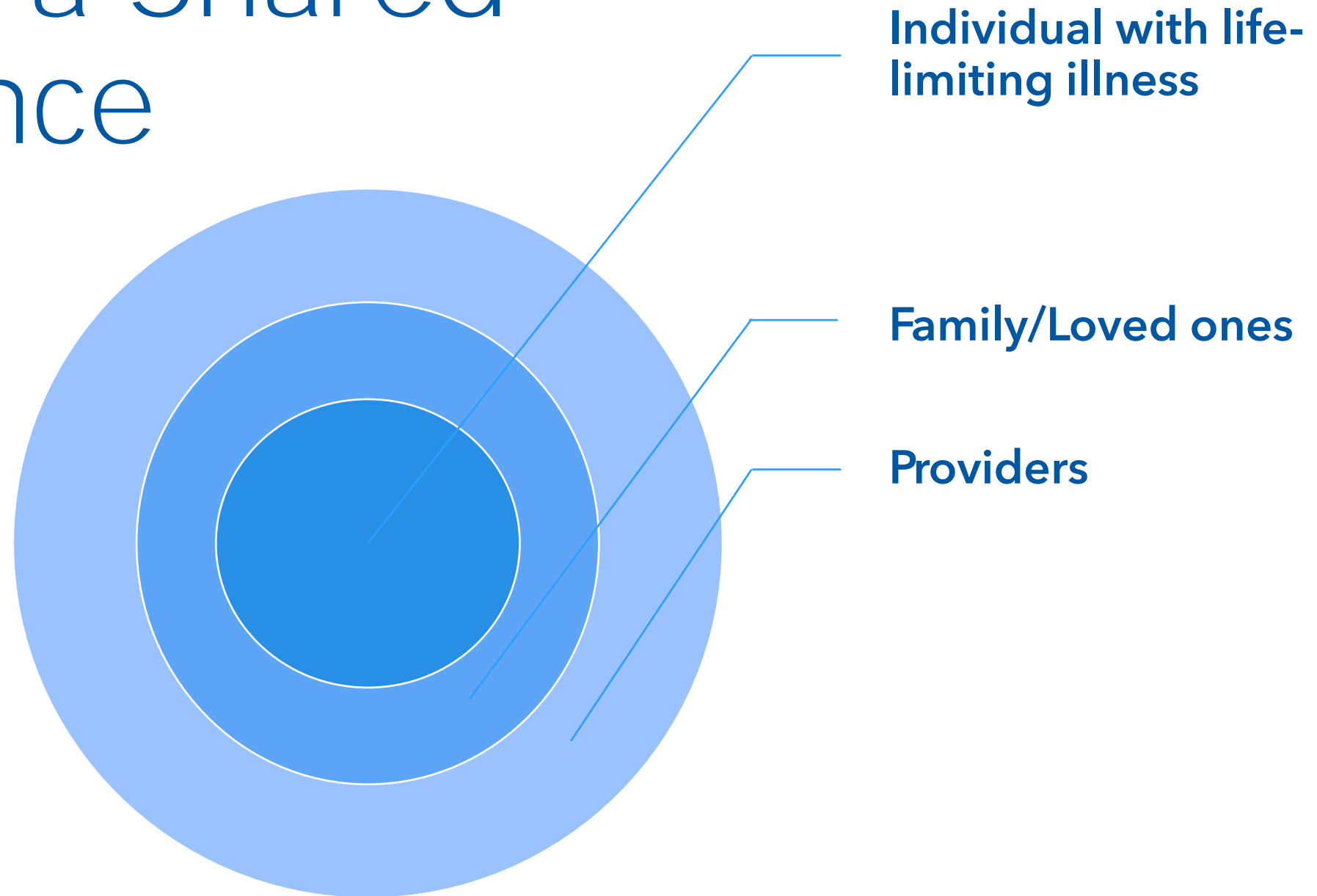


Course Objectives

To recognize the importance of:

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

Death is a Shared Experience



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?

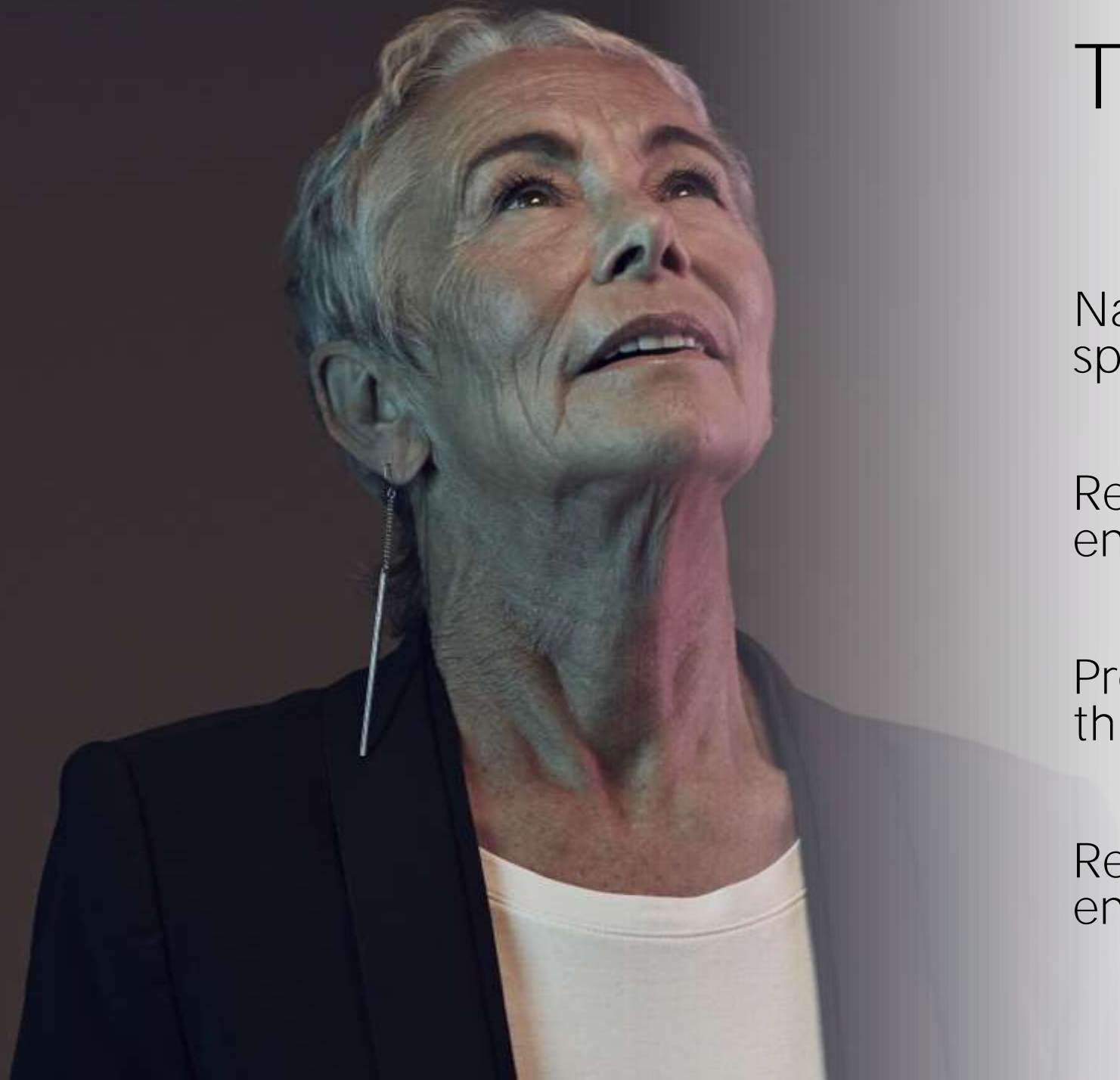
Death
is a
spiritual process with medical implications
rather than a
medical process with spiritual implications.



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

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

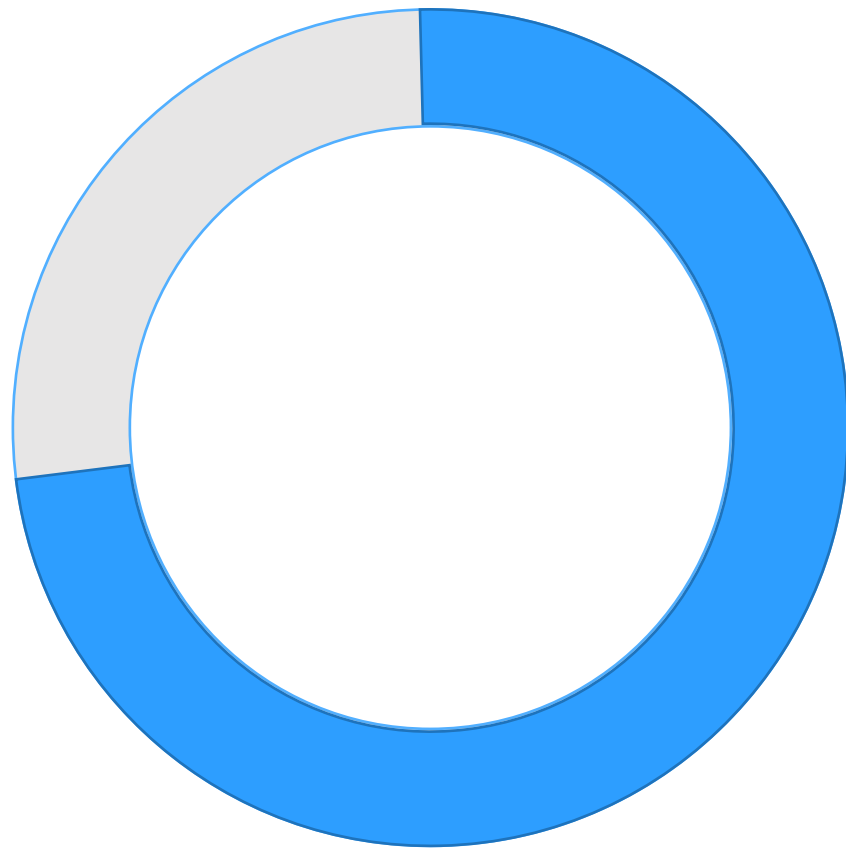
Spirituality/Religiosity

Looking forward

Quality of Life

A Life Worth Living

Death in the US



Deaths 65+: 2.5 million (approx. 72% of US deaths)

Adults 65+: 56 million (16.9% of US population)

2021 Total Annual Deaths:

3.46 million

(Ahmad et al., 2022, [Americas.healthrankings.org](https://americas.healthrankings.org))

	Death in 1900	Death in 2021
Life Expectancy	47.3 years old	76.4 years old (2021, lowest since 1996)
Cause of Death	<u>Infectious Disease</u> Smallpox, influenza, scarlet fever, pneumonia	<u>Degenerative/Chronic disease</u> Heart disease, cancer, COVID-19, stroke, lung disease, dementia
Trajectory	Rapid, brief (days, weeks)	Slow decline (months, years)*
Location	80% at home Only poor died in institutions	66.5% 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

Models of Care



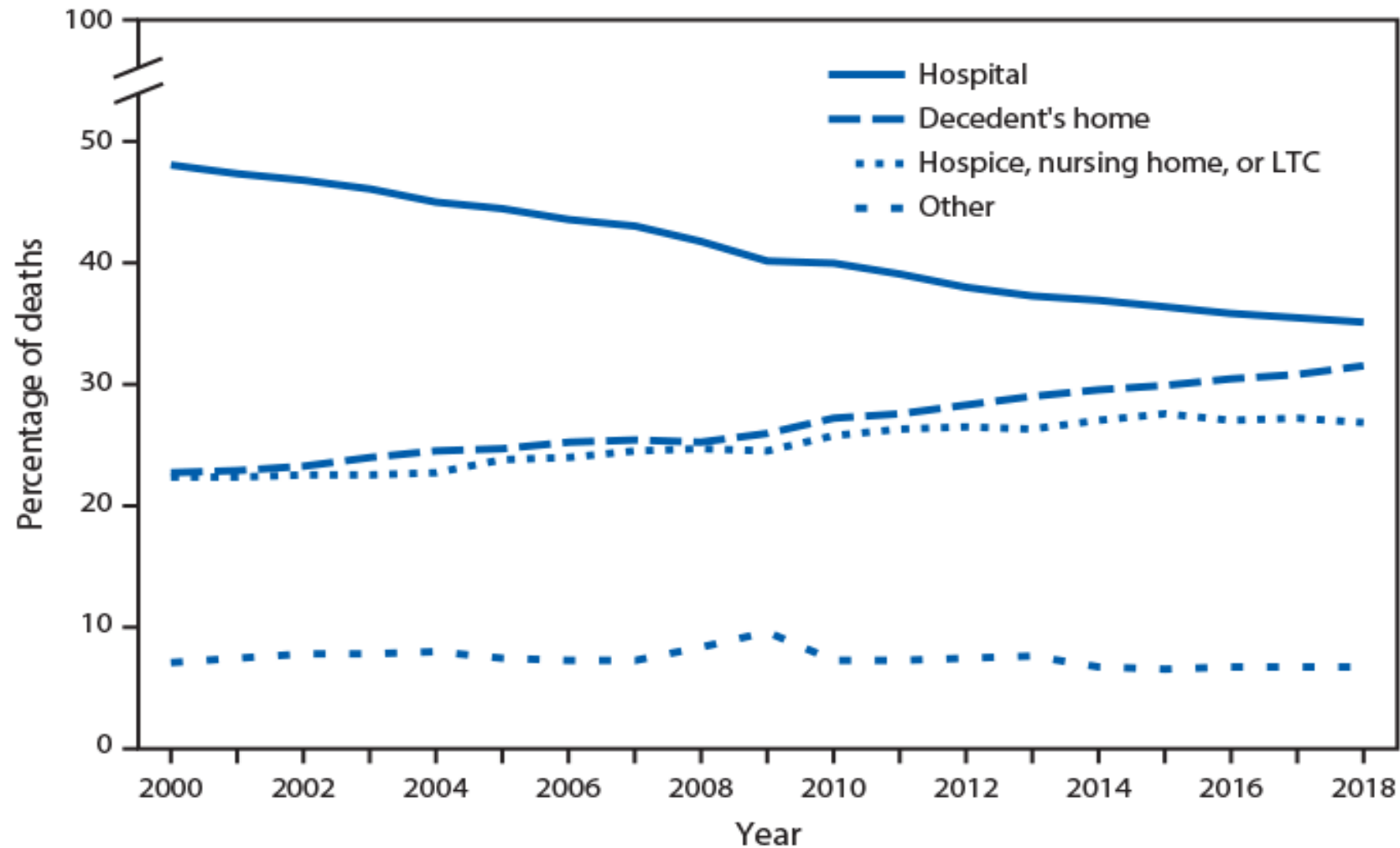


POLL

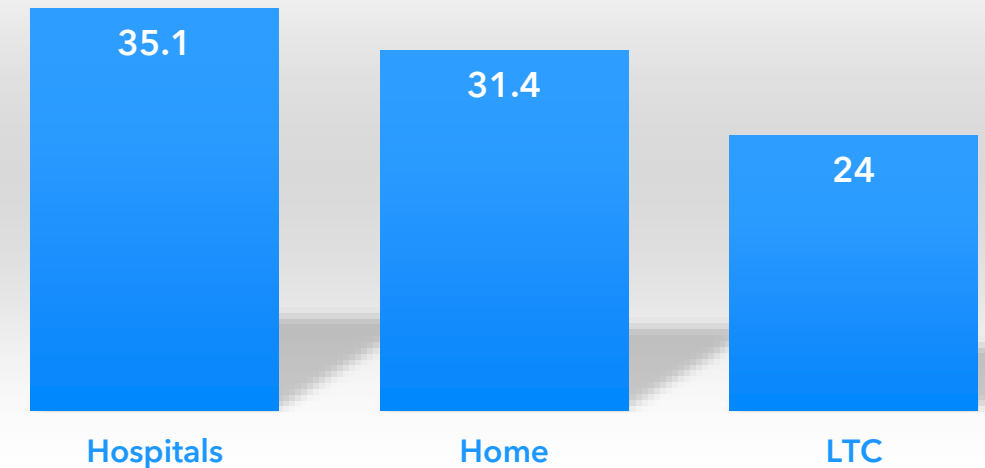
Have you ever had a loved one
pass away...

- ☐ At home?
- ☐ In a hospital?
- ☐ In long term care?
- ☐ In hospice care?

Where Older Adults Die



Where Older Adults Die (%)



Hospitals (Acute)

35.1% 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.

Most common setting for palliative care.

Long Term Care

24% of deaths occur in long-term care facilities. (Up from approx. 22%)

Residential setting and family-like caring relationships

Focus of care and reimbursement based on restorative and maintenance goal

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.
Knows patients well
Limited training

Family expectations often exceed facility capabilities.

Determining death trajectory complicated.

Partnerships with hospice care beneficial.

Home

34.1% of deaths occur at home and are expected to increase

Familiar comforting setting and caring family relationships

Can be burdensome and troubling for caregivers

Not viable over time without dedicated caregiver(s)

Works best with hospice care support



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

Dictionary.com

Palliative Care

A conceptual image featuring a person standing on a long, wide staircase that leads up to a large, illuminated pyramid structure. The scene is set against a dark blue background, with the pyramid and stairs glowing with a soft, warm light. The person is positioned on the lower steps, looking up towards the pyramid. The overall mood is contemplative and hopeful.

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



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

A person is lying in bed, partially covered by a white blanket. Their hand is near their face, and they appear to be resting or sleeping. The background is a soft, out-of-focus white.

Hospice

Compassionate End of Life Care

**Hospice isn't about giving up.
It's about changing tactics.**

It's about comfort and quality of life.



Hospice is Not a Place

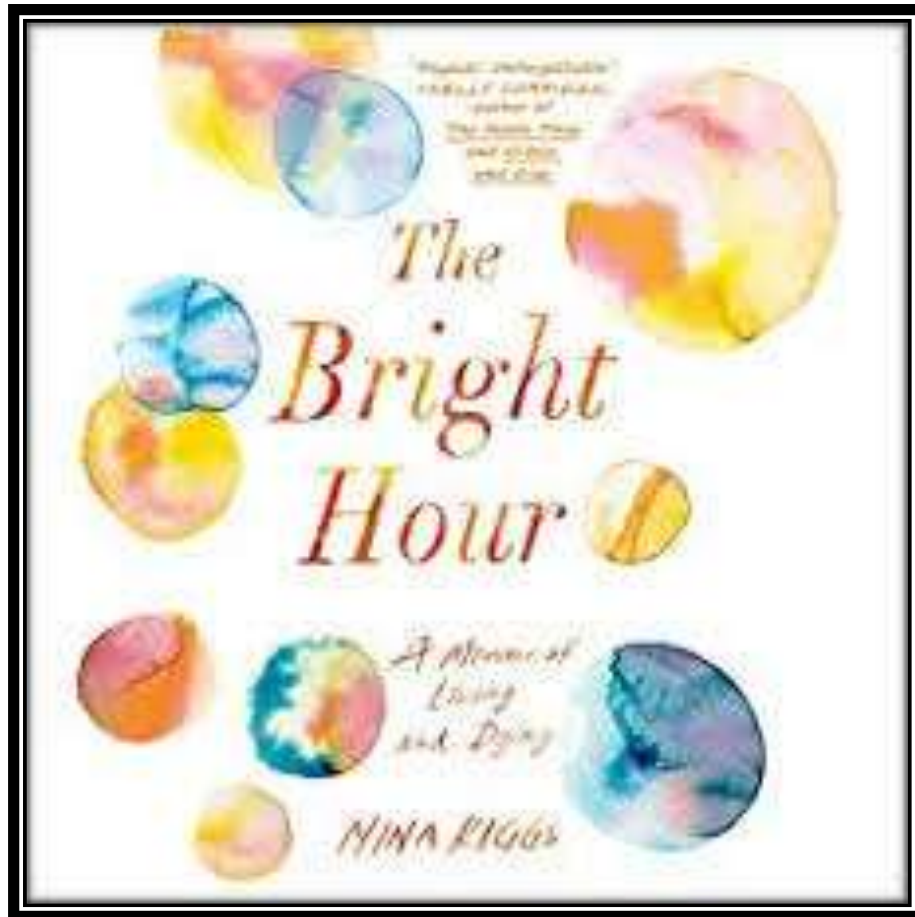
But a holistic model for compassionate, quality care for individuals facing a life-limiting illness or injury.

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.

Most widely used form of palliative care.

Nina writing about her mother



"We have called in hospice for my mom. It's strange, because hospice is one of those words that when you say it people's faces fall. It is a word that evokes last breaths and hushed voices. But the more I think about it, the more I'm struck by what a beautiful word it is – hospice. It is hushed especially at the end. But it's comfortable and competent sounding too. A French word with Latin roots – very close to hospital, but with so much more serenity due to those S sounds. It used to mean a rest house for travelers - for pilgrims. And is there anything more welcome to a weary pilgrim than rest?"

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.

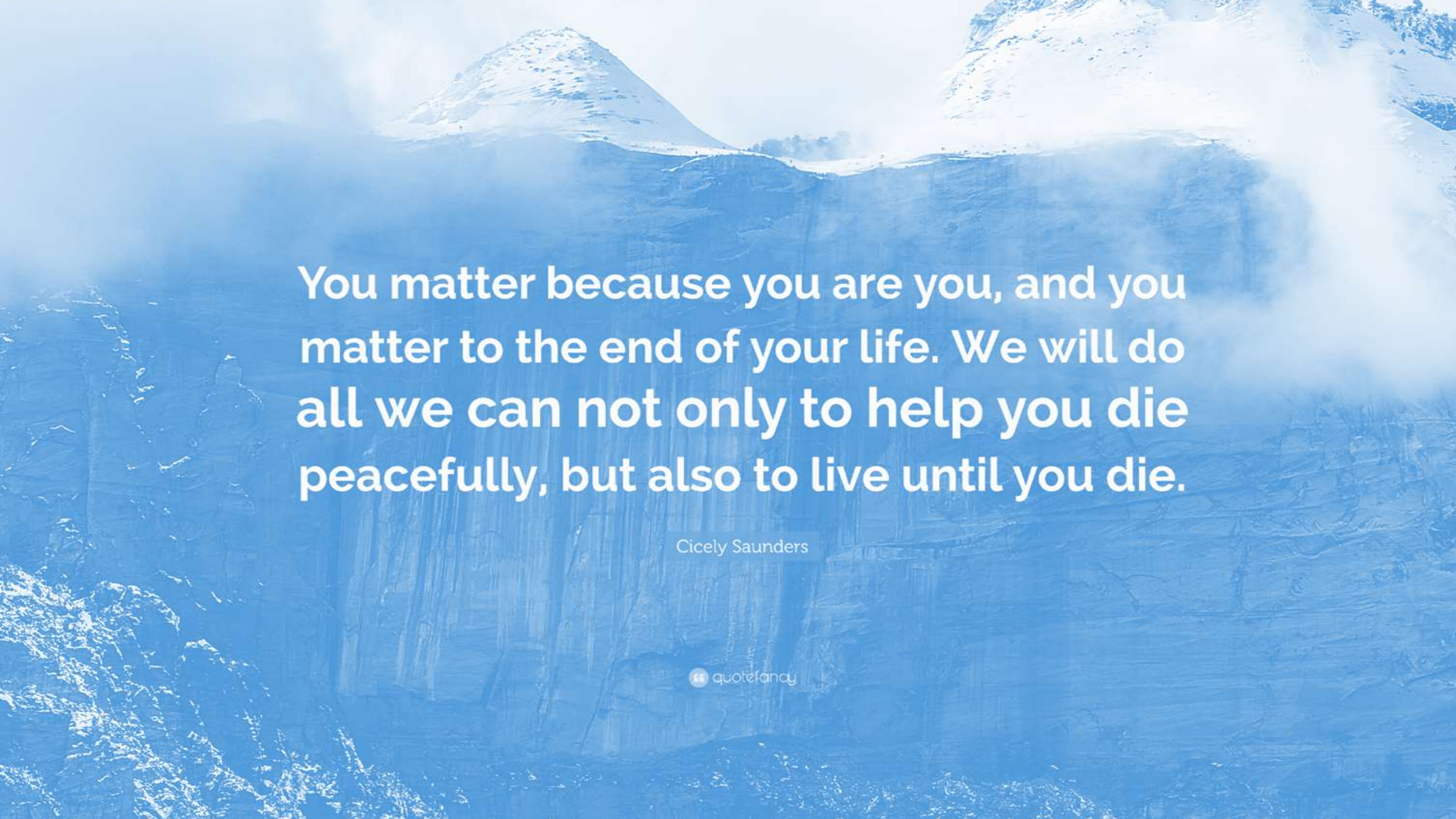


Support is provided to the patient's loved ones as well.



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.





You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

Cicely Saunders

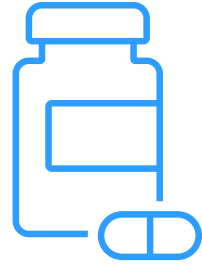
 quote fancy

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.
- Approx. 50% of decedents are under hospice care at time of death.



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

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 its normal course

Acceptance of comfort care instead of aggressive treatment for terminal illness

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

"Wherever Home Is"



Overview of Services



Hospice Core Team Services

Medications related to the terminal illness *and* pain and symptom management.

Medical Equipment (DME)

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

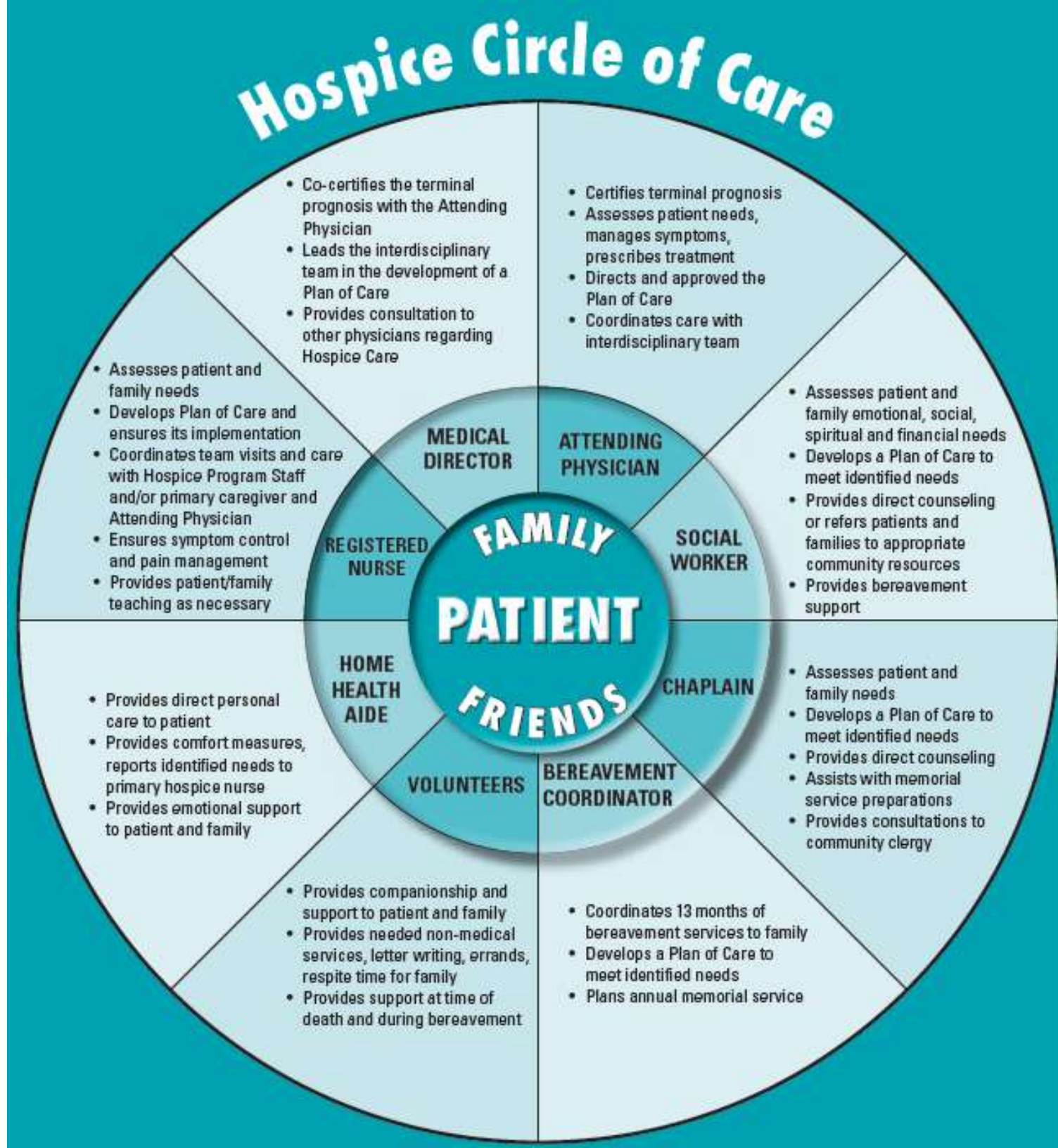
Special services as needed (speech, PT)

Short-term in-patient care for symptom/pain management or family respite.

Emotional and bereavement support to family.

Interdisciplinary Team

- Medical Director
- Attending Physician
- Registered Nurse
- Home Health Aide
- Social Worker
- Chaplain
- Volunteers
- Bereavement Coordinator





Benefits of Hospice Care

Extended life over “usual care” patients (approx. 29 days)

Reduction in overall healthcare usage

Reduction in hospitalization; Less hospital deaths

Higher care satisfaction, patients and family

Higher perceived quality of life

Families and patients feel more supported and less isolated

Lessens grief after death



Barriers to Hospice Care

Reluctance to terminate life-saving interventions

Reluctance of health care professionals to have the conversation

Difficulty of determining 6 months prognosis

Stigma

Misconception of how it works

Social/Cultural beliefs



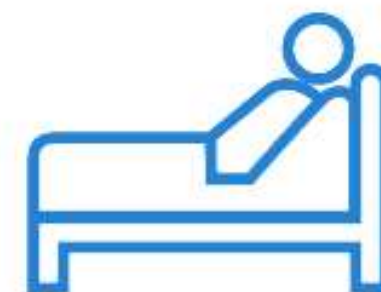
Palliative Services ●

Paid by
insurance, self

Any stage of disease

Same time as
curative treatment

Typically happens
in hospital



● Hospice Services

Paid by Medicare,
Medicaid, insurance

Prognosis 6 months
or less

Excludes curative
treatment

Wherever patient
calls home

Older Adults & Advance Care Planning

"It's too early until it's too late."

The Conversation Project



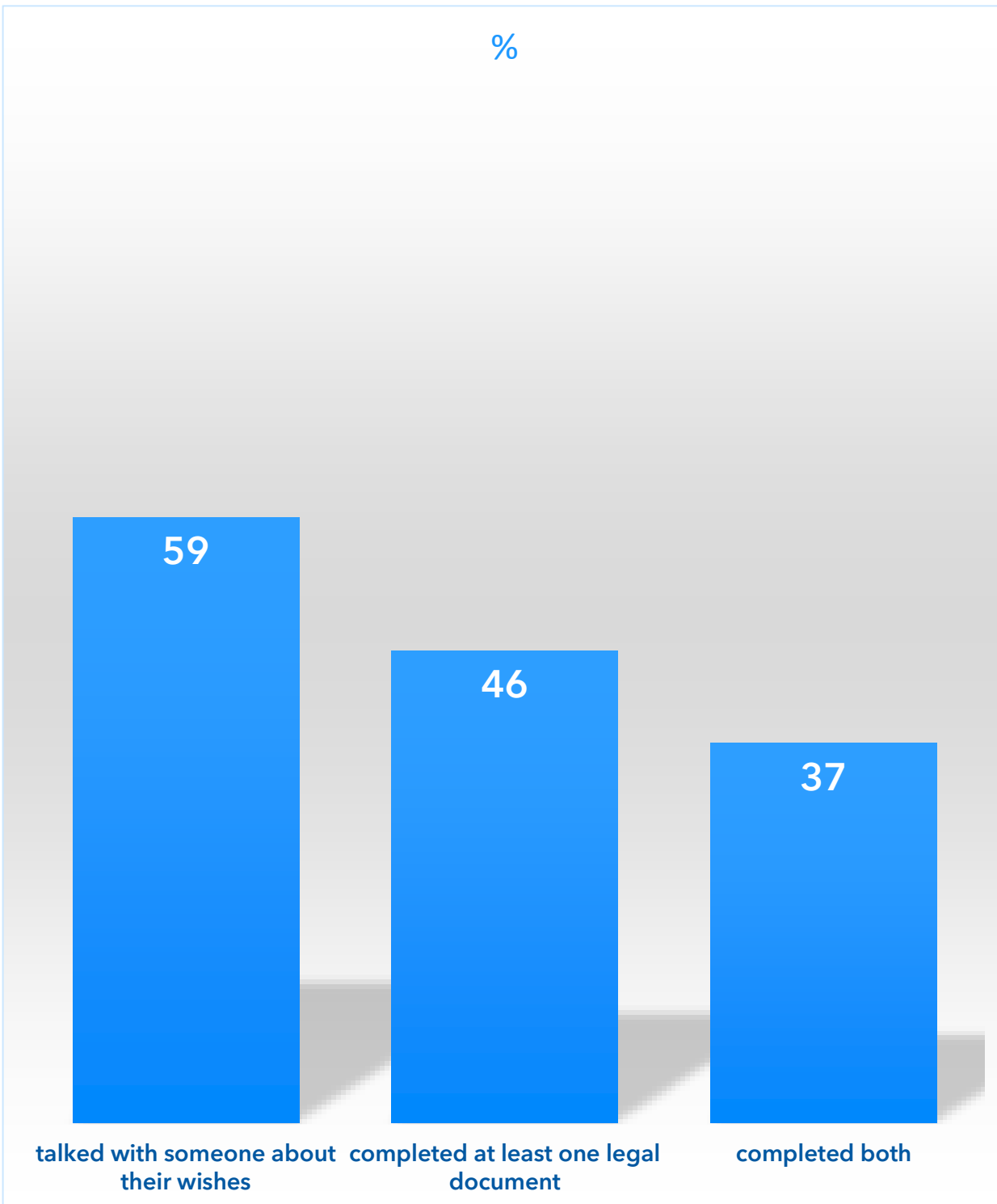


POLL

Do you have an Advance Care Plan?

- ☐ No I don't have one.
- ☐ Yes I have one.
 - ☐ Living Will?
 - ☐ Health Care Power of Attorney?
- ☐ If you have assigned a health care agent, does he or she know your health care preferences and goals and values?

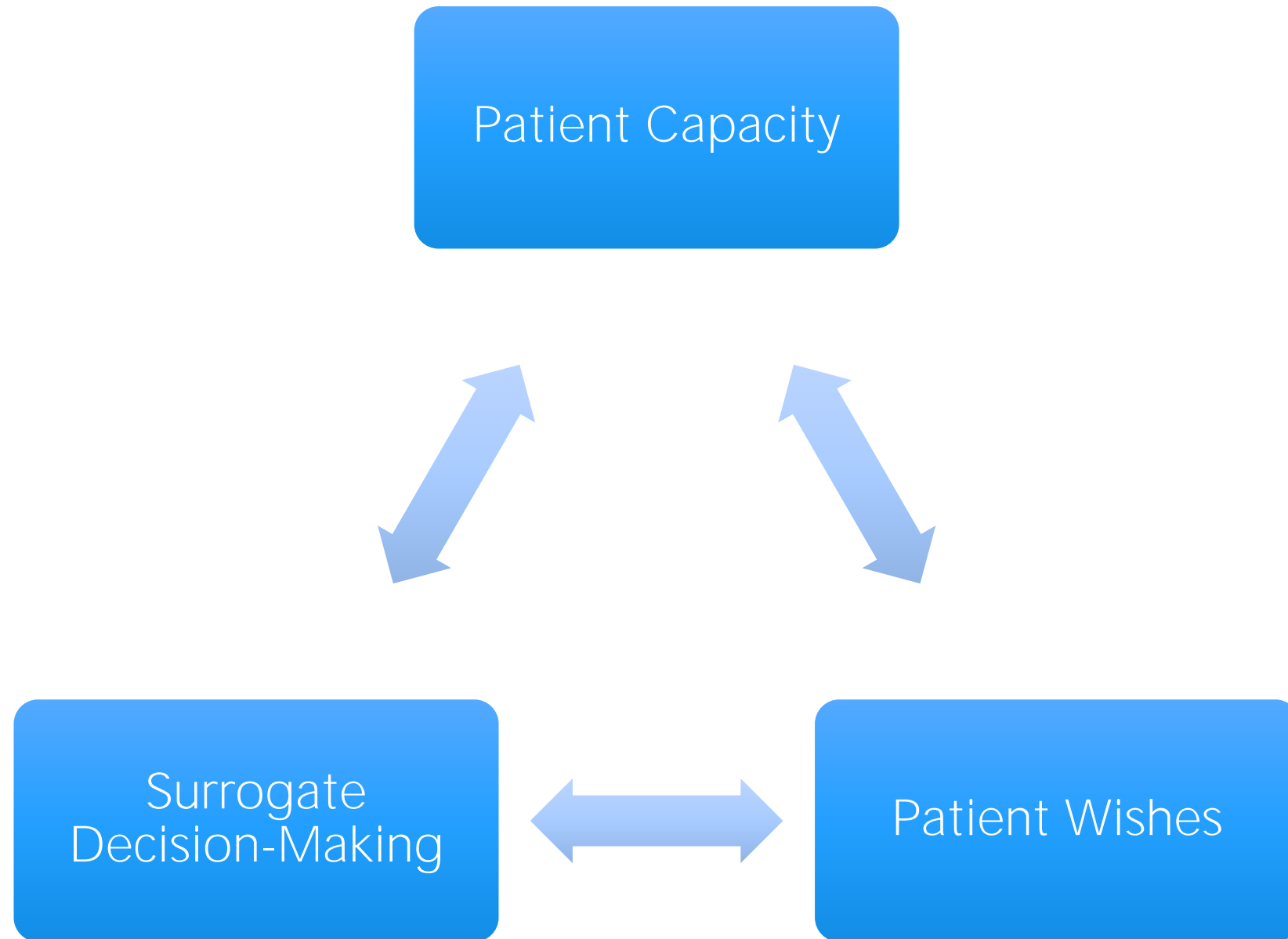
ACP & Older Adults



What is an Advance Directive?

- Decision-making tool for an incapacitated individual.
- Two-pronged approach that allows an individual to guide their care **when they can't speak for themselves.**
- Focus on patient goals and values
- Primary elements:
 - Patient Preferences: *Living Will*
 - Surrogate Decision-Making: *Health Care Agent*

Decision-Making Triad



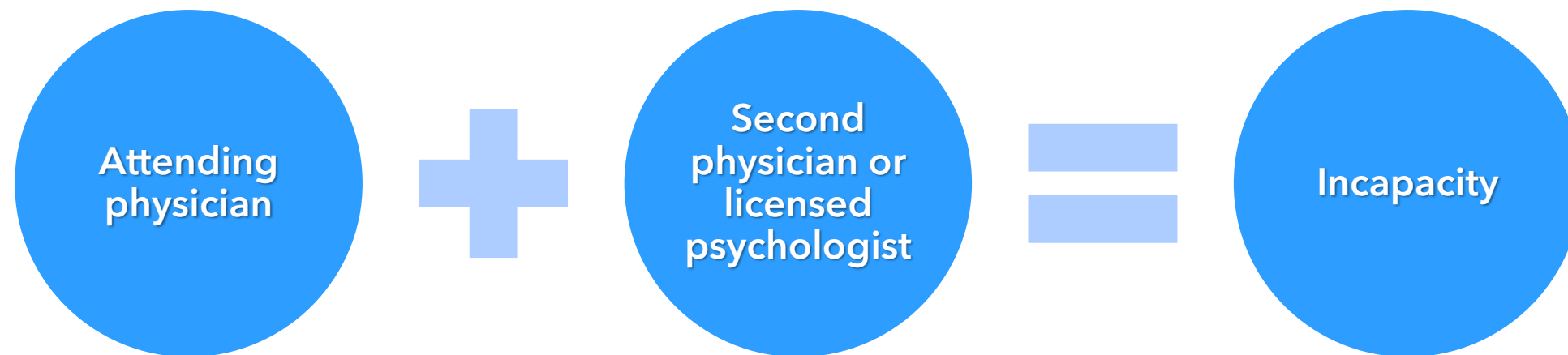
Patient Wishes: Living Will

- Outlines an individual's care wishes regarding care. Usually narrowly defined range of circumstances.
- Guides health care providers and family members in their decision-making
- Can include both the administering and the withholding of life-sustaining treatment.

<https://www.vsb.org/site/public/healthcare-decisions-day/https://theconversationproject.org/get-started>)

Patient Capacity

- Capacity: patient's ability to understand risks and benefits of treatment decisions and to make decisions regarding their care.
- A diagnosis alone is not enough to make the determination.
- Determination differs from state to state.
- VA requires two physicians to declare a patient incapacitated except for when the patient is unconscious or in an acute status



Surrogate-Decision Making

Health Care Agent

- the individual authorized to make decisions
- **"Extension of the patient"**
- Should set aside their own health care philosophy

Health Care Power of Attorney - the legal document that grants that authority.

Laws in most states prohibit individuals from appointing their physicians as their health care agent, although Virginia does not.

The Steps

Remember & Reflect

- Experience from others illnesses, what did you learn?

Define Quality of Life

- What activities or experiences are most important to you?
- How does your faith, cultural or personal beliefs factor in?

Choose a Decision Maker

- Who would most likely carry out your wishes?

Ask the Person

- Are they willing?
- Be sure to discuss goals and values

Complete the documents

- Define health care desires

(honoringchoices-va.org, theconversationproject.org/getstarted,
vsb.org/site/public/healthcare-decisions-day, theconversationproject.org/get-started)

Types

TRADITIONAL

State Forms – almost all states have a standardized form; requires a witness over the age of 18

Attorney generated – not necessary but often used; best with complicated medical conditions; usually notarized

Oral – only valid with a terminal condition and stated directly to a doctor

POLST or POST – Medical order

ALTERNATIVE OPTIONS

My Living Voice

Five Wishes



Benefits of ACP

Helps ensure care is consistent with preferences

Increases the likelihood that wishes are understood and carried out by providers and family

Increases family satisfaction and lessens grief

Reduces hospitalizations and increases hospice enrollment

Fewer hospital and ICU deaths

Enhances EOL care for dementia patients

Improves outcome while decreasing health care expenditures

Barriers to ACP

“Don’t get around to it”

Perceived as complicated and difficult to execute

No clear path to execution

Patients expect physicians to initiate but physicians lack time and training

Misconceptions about their purpose

Confusion around provisions

Reluctance to discuss “death”

Cultural differences

PRACTICE PAUSE

Share Highlights of Your Experiences

What do you know now that you wished you'd known earlier?

Key takeaways from the Death & Dying sessions?

What do you feel you still need to know?



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