The Perfect Hospice Patient

NECHH

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Objectives:

- Discuss six types of psychosocial issues at end of life and how to address each one
- Think objectively to realize that every patient and family is different, with different needs
- How to use Listening Skills
- How to lead the patient and family to peace for a "good death."

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DNR

They have a clean and safe home

At peace with diagnoses

Able and willing caregiver

Supportive family

Sufficient funds for all needs

Compliant patient

Strong faith

They understand all meds

Pain is always under control

No family turmoil/drama

Funeral plans in place/paid for

No fear of death

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"One problem can be that medical science has become so adept at propping up failing bodies that the realization that death is approaching may not be so apparent."

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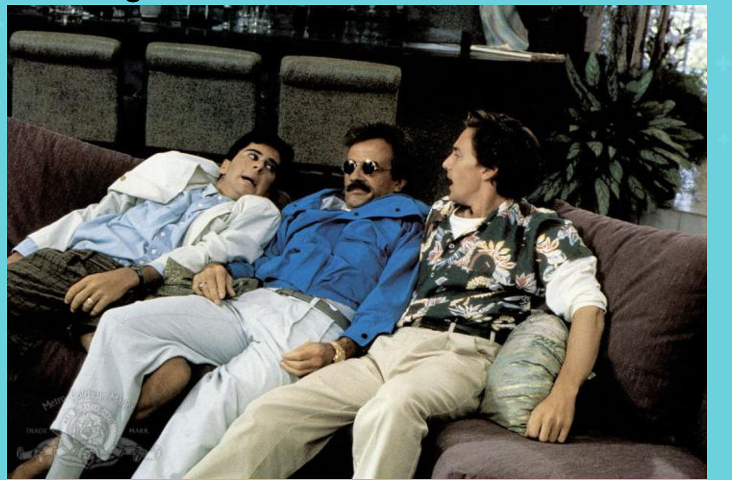

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EMOTIONAL ISSUES

- **Sadness of what you'll miss out on in the future**
- **Guilt of being better off and out of pain**
- **Guilt of leaving unfinished business for others**
- **Shame for needing and relying on others through disease process, decline, and death**
- **Anger of failed treatment, let down from MD, injustice, "why me."**
- **Fear, anxiety, and loneliness**
- **Helplessness of the present crisis**

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How to cope with losing the life we expected?

- Talk- self talk, friend, family member, spiritual advisor, hospice team member
- Connect Spiritually
- Confront your anger and address it-Anger is a response to fear
- Ask- WHY you're afraid to die
- Adding medications for anxiety
- Write Letters and make videos-this helps you AND your loved ones

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Sexual Changes at End of Life

Change in roles

Change in body/self image

Lack of desire

Lack of functioning ability

Fear of pain for both patient and partner

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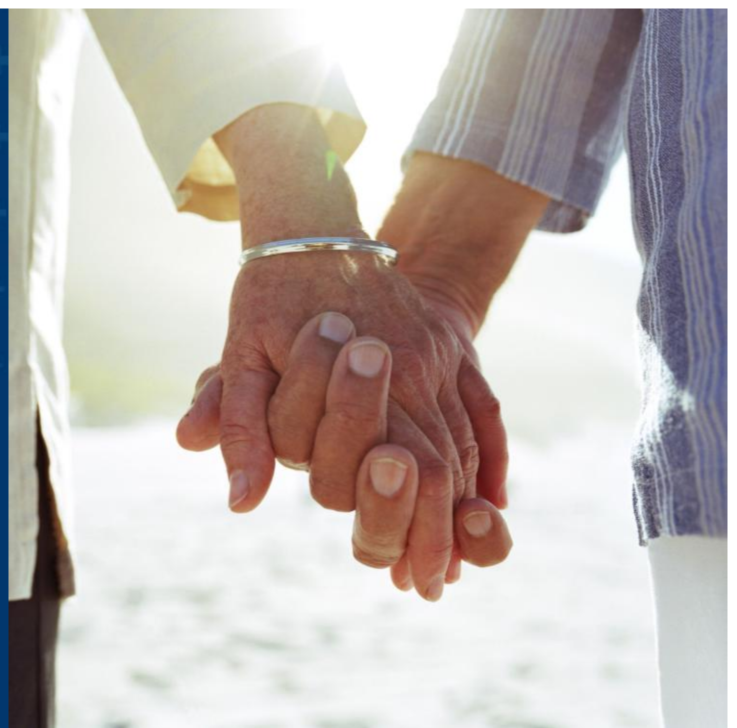
Needs of a Couple

Lack of sexual intimacy is just one of the many losses couples go through

Partners have become the caregivers and may have a difficult time seeing the patient “that way”

Providing care is exhausting, sometimes causing a lack of sexual desire

Distancing themselves to “make it easier” and get used to



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How to address…

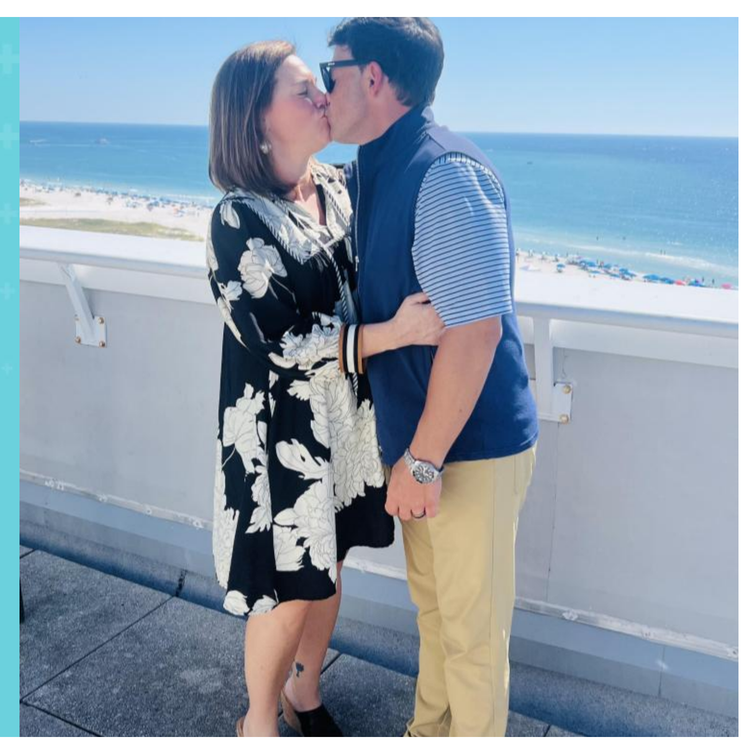
Give permission to each other to touch

Privacy- limit company or hospice team certain days/times

Encourage other kinds of intimacy such as bathing together or light massage

Medication Management

Get creative with pillows and positioning for SOB and pain



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IDT Support

YES, sex DOES matter, even at end of life

We must support this need as much as any of the others

Sexual Intimacy must be normalized by the IDT

It may the only thing they can still control or give to their partner

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5 Universal Ethical Principles

Autonomy- Independent decision making

Beneficence- Doing good for our patients

Nonmaleficence- Do no harm and prioritizing patient care

Fidelity- Being loyal or faithful

Justice- Fair and just treatment

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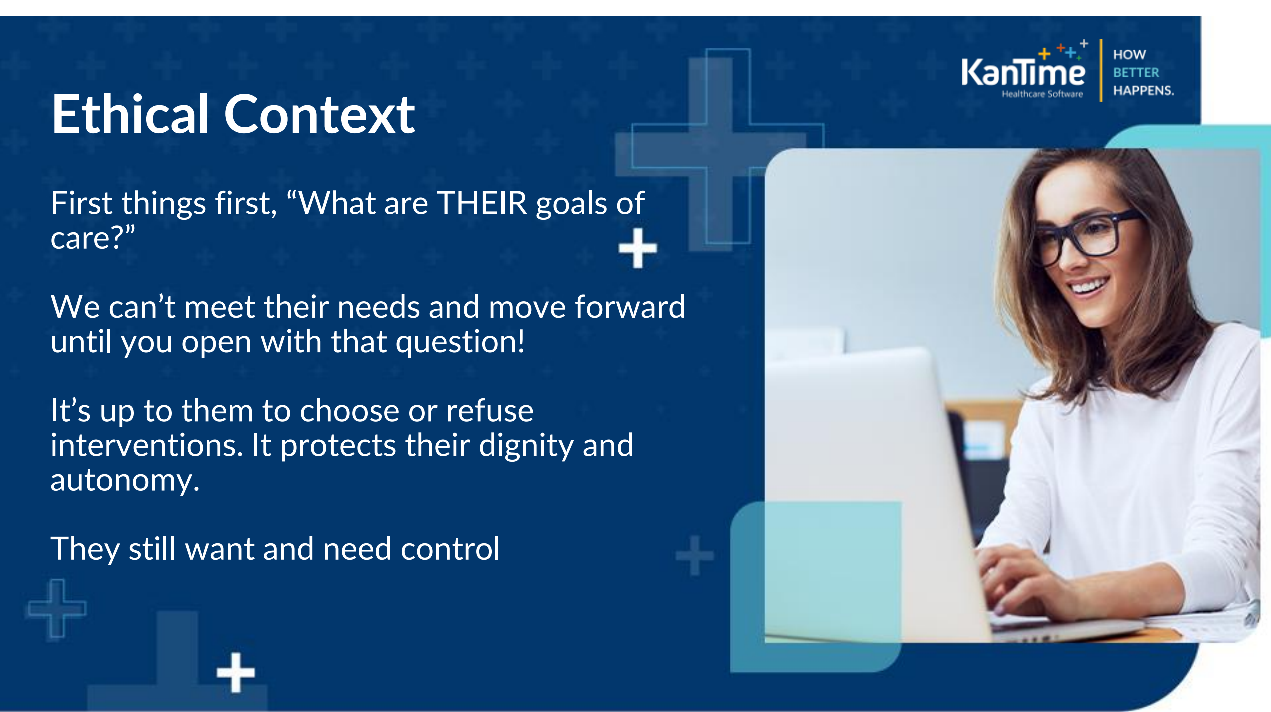

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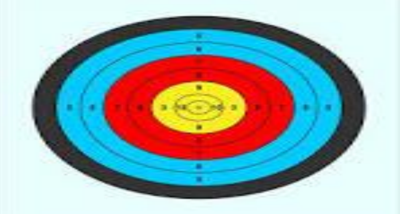
What is "The Golden Rule?"

Goals of Care

Goals of care for terminally ill patients:
Alleviate suffering
Optimize Quality of Life until death
Provide comfort in death

Open communication and shared decision-making among health care providers, patients, and families would avoid many of the ethical dilemmas at end-of-life care.



Physicians, patients, and patients' family members have to make decisions regarding treatment options such as whether to prolong a person's life with the support or allow the natural death process to continue, they face various ethical dilemmas related to end-of-life care.

Quality vs. Quantity

The Dilemma:
Medical advancements can prolong life, but this raises questions about the "quality" of that extended life and whether the treatments are a benefit or a burden.
(Back to Bernie)

Challenges:
Determining if a treatment is medically futile (unlikely to provide meaningful benefit) is a significant ethical challenge.

Considerations:
This includes decisions about life support, artificial nutrition and hydration, and palliative sedation. The goal is to balance the benefits of prolonging life with the patient's comfort and potential suffering.

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Questions for the Patient

1. How important is staying mentally alert to you in the final days before death?

2. What pain level are you willing to endure?

3. What type of pain medicine or alternatives should be considered?

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Resource Allocation and Justice

The Dilemma:
Healthcare resources are not infinite, and complex end-of-life care can be costly.

Challenges:
There's an ethical responsibility to use resources justly and to ensure that patients receive equitable access to care.

Considerations:
Ethical dilemmas arise when considering how to allocate limited resources, such as hospital beds, specialized equipment, or access to palliative care services, particularly in cases of medical futility or when care is in short supply.

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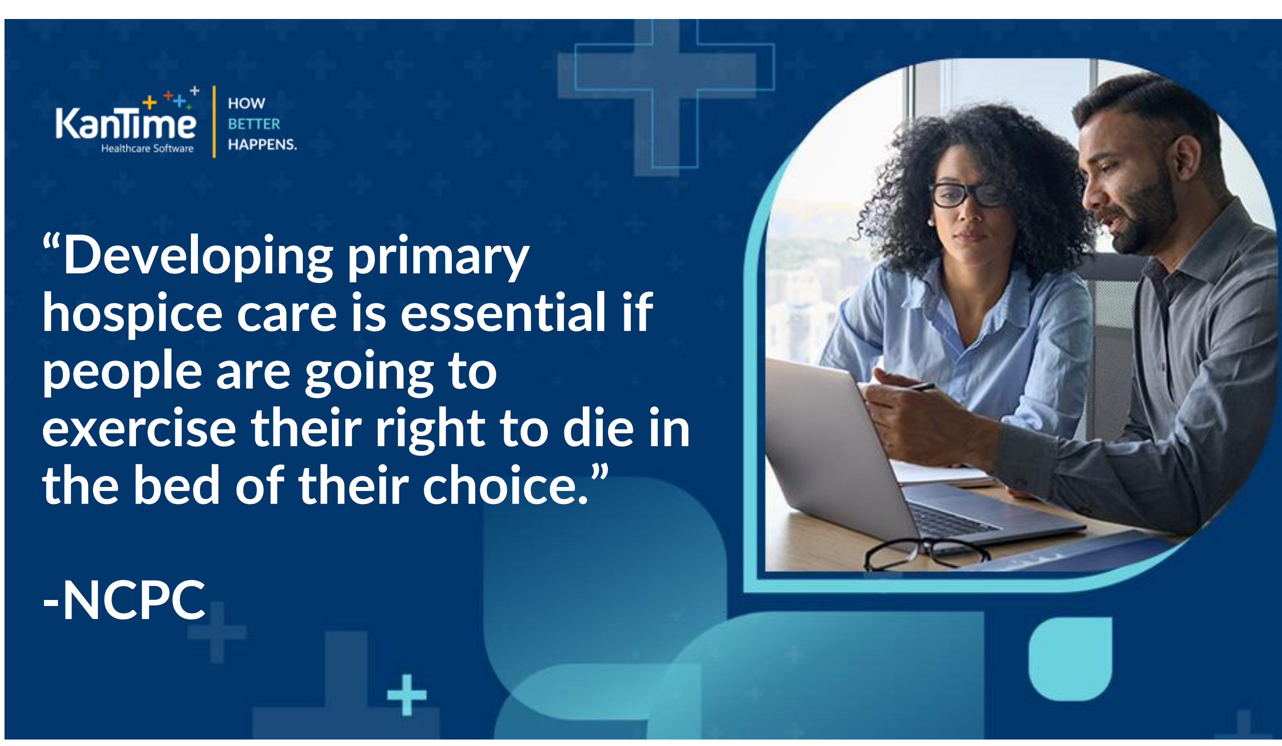

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Cultural Issues

What is Cultural Pain?
The influence of cultural background on the experience and expression of pain

Cultural pain/distress can be expressed through physical, psychosocial, social, and spiritual pain. Often times spiritual/religious beliefs have a strong bearing on how a diagnosis is interpreted. Example: Miracles

There are variations of religions, faiths, ethnic backgrounds and how they approach end of life.

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- **Many cultures also have distinct cultural beliefs regarding the meaning, origin, and role of pain, which can affect how a patient interprets and perceives pain.**
  - African, Asian, Chinese, East Indian, Hispanic, Indonesian, Japanese, Native American, and Vietnamese families may request providers not to disclose a terminal diagnosis as they want to avoid emotional suffering and preserve hope.
  - For Christian Scientists, Hinduism, Jehovah's Witnesses, Mormons, Muslims, and Seventh-day Adventists, it is considered contrary to the church's teachings to euthanasia and possible use of drugs that may hasten death.
  - Members of the Buddha religion may not want any drugs that cloud the mind near death.
  - Taiwanese may believe that bad luck occurs if one discusses impending death out loud and, as a result, avoid discussing death to tempt fate.

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Psychosocial Care addresses the psychological experiences of loss and facing death for the patient and their impact on those close to them. Are we assessing this for the caregiver as well?

Spiritual Issues

Culture

Values concerned with social factors

Practical aspects of care including financial

Housing and ADL's

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Psychosocial Issues

FIRST thing to ask: Tell me your story…

LISTEN and LEARN to the history of their illness and let them identify their concerns/needs and coping skills.

Are these being addressed in IDT to provide intervention?

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This effects coping, psychological adjustments, and communication with both the patient and family.

- Neurological diseases can lead to communication difficulties adding a whole different dynamic, especially when they are cognitively sound.

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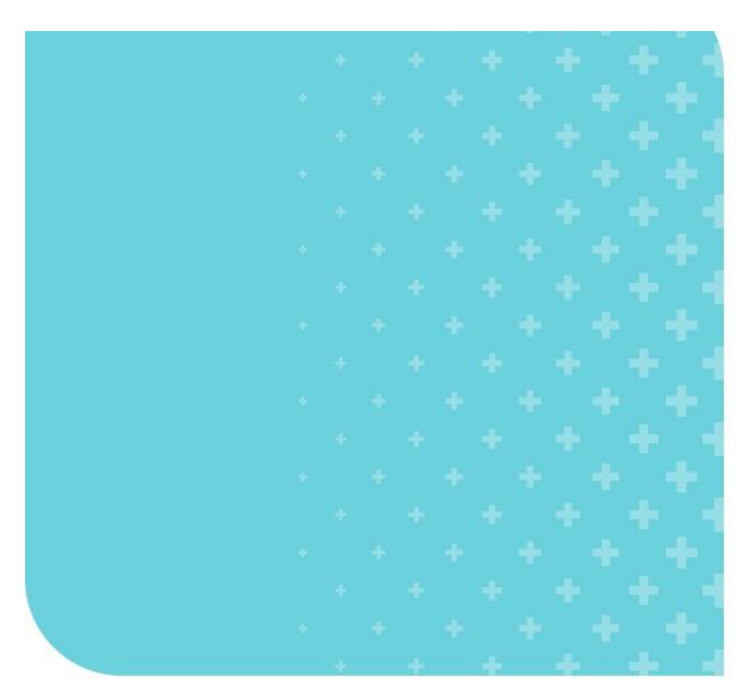
SOCIAL CONTEXTS

How would life change for you socially if you have a terminal illness?



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Travel

Sporting Events

Holiday Parties

Family Gatherings

Attending Church in Person

Normal daily errands/shopping

Date nights

Not able to continue your career

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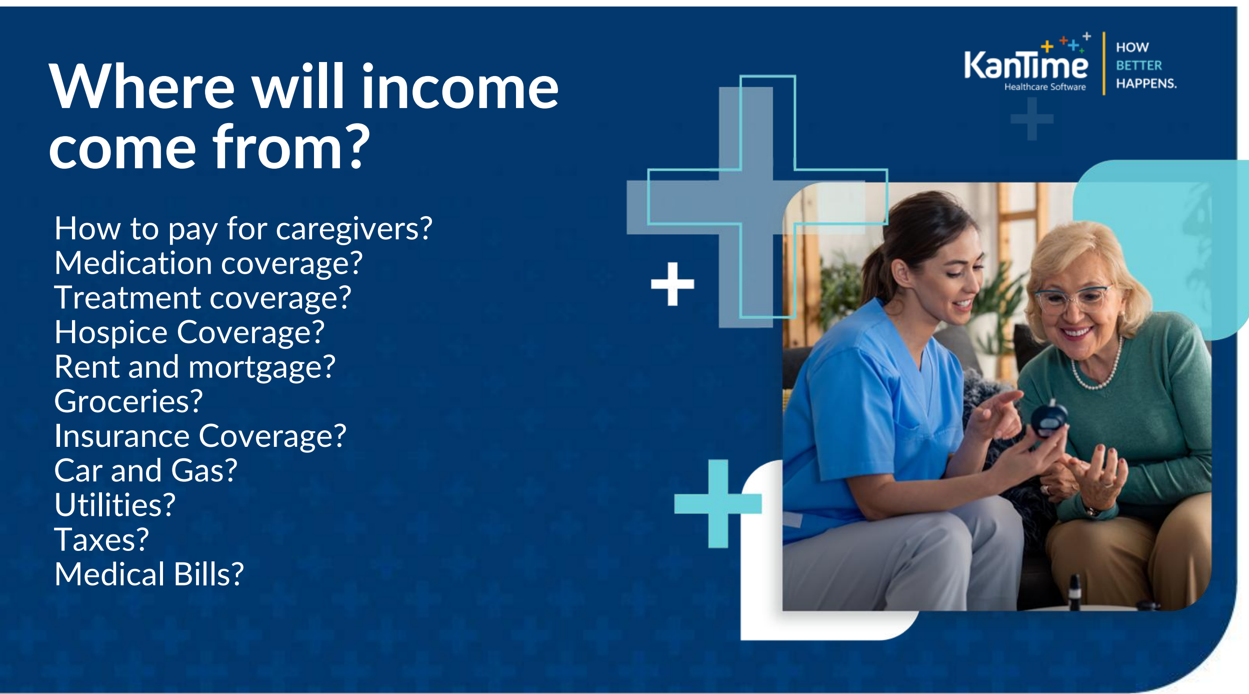

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Social Changes

Incurable illnesses change the social status of the patient.

Other than pain and other devastating symptoms, patients may suffer from the undesirable effects of the disease that affect the patient's appearance; the loss of social, professional, and familial roles; the ability to remain independent and function normally, and most importantly the perception of the future.

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Social Issues

- Our society and social media show us Cancer battles and acknowledge the "warriors" of this awful disease.
- We should acknowledge ALL of the battles being fought, won, lost, and the caregivers that provide the love and support needed through each day!
- Fundraising for all diagnosis and treatments
- Support Groups are growing for EVERY kind of diagnosis and caregiver

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In closing…

We MUST educate and support!

-Understand-Symptoms, disease process, and dying process

Acceptance-Regardless of mood, social ability, and appearance

-Self Esteem-Involvement in decision making

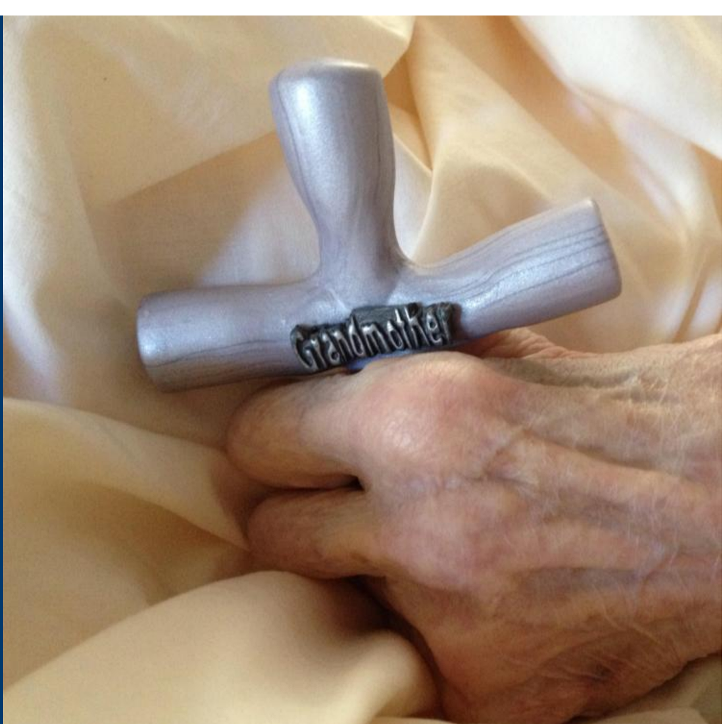
-Safety-feeling secure in all relationships

-Belonging-Feeling needed and not a burden

-Love-Expressions of affection and human touch

-Spirituality-meaning and purpose, religious or not

-Hope-any improvement in any aspect of life



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HERE IS A SECRET…

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There is no “perfect hospice patient”

We must meet our patients and families where THEY are.

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