

# Terms of Engagement for End-of-Life Discussion

#### Ground rules for maintaining dignity:

- Dignity is bestowed on patients through the certainty of being provided the right care at the appropriate time.
- Patients have the right to choose how they die, but cannot choose to not die.
- Patients die from terminal medical illness, not by personal wishes or perceived failings.
- Provisions for the end-of-life journey are standard ethical practice of medicine.
- Palliative care or conservative intervention is administered during end-stage disease with patient discretion. Patients choose to do and not die or to not do and end suffering sooner. Palliative care as compassionate care allows patients their choice of medical intervention.
- End-of-life care or comfort care is given once the futility of medical intervention is determined. End-of-life care as compassionate care is not a choice, it's a matter of comfort.
- End-of Life care is equated and engaged as Hospice or Omega care:

HOSPICE CARE	OMEGA CARE
Affirms Life	Affirms Rite of Passage
Hope Lingers in Limbo	Hope Dissipates through Bliss
Open-Ended Wishes	End-of-Life Wishes
Create Confusion	Create Certainty
Patient-Focused Care	Person-Focused Care
Monitoring Vital Signs —	Dismissing Vital Signs —
Objective Care	Subjective Care
Curative Care Optional	Curative Care Unnecessary
Intervention as Necessary	Rest in Peace
Physician Primary	Nurse Primary
Nurse Supportive	Physician Supportive
Compassion Requires Consent	Compassion is Understood
Halfhearted Passive Euthanasia	Heartfelt Passive Euthanasia
Fear in Administering Mercy	No Fear in Administering Mercy
Queries Meaningful Life	Honors Fulfilled Life

#### More discussion regarding Omega care is included in Wishes To Die For, available on Amazon.com

#### Timeframe for ending unnecessary intervention:

- End-of-life counseling begins with the diagnosis of end-stage disease.
- Determination of end-stage disease informs patients of their impending cause of death.
- There is an expected natural progression of end-stage disease and optional consideration given to avert prolonging life.
- Knowledge of end-stage disease informs patients that time is of the essence.
- The diagnosis of end-stage disease jumpstarts advance care planning to enactment
- Care plans that are negotiated and initiated at the outset of end-stage disease
- Patients are counseled on the merits of conservative palliative care and discouraged from receiving unnecessary medical intervention.

- Patients are empowered to not treat other disease such as infection, hypertension, diabetes or heart conditions that simply prolong the process of dying and undue suffering.
- Patient and caregivers become cognizant that when the patient takes a turn for the worse, end-of-life care is provided. There is no turning back to aggressive treatment or ICU admission.
- The turning point from palliative care to end-of-life care has a particular time and purposeful intention.
- The particular time given to end-of-life care is when end-stage disease prompts a 911 call and emergency department assessment. Presumably, end-stage disease has become unmanageable, the situation hopeless and consideration for comfort care is paramount.
- The intended purpose of end-of-life care is to designate personal responsibility for all involved:

#### Healthcare care providers evolve from dutiful to empathetic Family members evolve from guardians to guides Patients evolve from vulnerable to blessed

#### Introspection prior to discussion:

Self-fulfillment becomes the necessary objective associated with end-stage disease and advance care planning for end-of-life fulfillment more clear through contemplation:

- Do you prefer a stay vacation (home) or end-of-life getaway (spa destination)?
- What would this stay vacation or getaway vacation entail?
- Is the EOL journey best traversed by car, ship or plane; winding, smooth or expedient?
- Where is the desired final resting place for your remains?
- What is the desired epitaph of your life's legacy?

## Pretest for discussion questions:

Life-threatening questions posed by physicians require prior self-examination:

- Is it better to die heroically (treat terminal illness) or gracefully (retreat from fighting illness)?
- Do you prefer all life-saving measures (more is better) or a final retreat (less is more)?
- Do you need to hear from the doctor that there is nothing more that can be done or do you prefer to tell the doctor when you are done?
- What life challenges or medical disabilities would make living longer less desirable?
- Do you value receiving or deferring investigative testing?
- Do you value objective medical recommendation or physician personal opinion?
- Are your wishes geared toward other's intervention or personal empowerment?
- Are you willing to refuse treatment and go against medical advice?
- With having end-stage disease, is it important to have other disease addressed?
- Is it important that you remain informed of your options as your medical condition worsens or be allowed to rest in peace during this time?

## Heartening conversation leading to peaceful resolution:

- End-stage disease is not the end of life, it's the beginning of end-of-life discussion.
- Avoiding "the talk" about death and dying is certain to leave patients and caregivers in the dark, powerless and isolated.
- Having the opportunity to have one's say and be heard during the end-of-life process creates an awakening for patients, healthcare providers and caregivers leading to the realization of priorities and what is most important.
- Final words and personal wishes for a good death need to be discussed at the beginning of end-stage illness and realized when death is imminent.



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