Palliative Care & Hospice Conference

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Palliative (Supportive) Care:

- Palliative care is an approach that improves the *quality of life* of patients and their families facing a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial and spiritual.
  - **WHO 2010**

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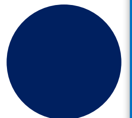

Why Palliative Care?

- To prevent and relieve suffering
- Help support the best possible quality of life for patients and families, regardless of stage of disease or need for other therapies.
  - **Can be offered with curative treatments or as the main focus of care**
- Both a philosophy of care and an organized, structured system for delivering care.
- Includes the goal of enhancing quality of life for patient and family.

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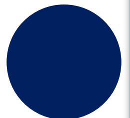
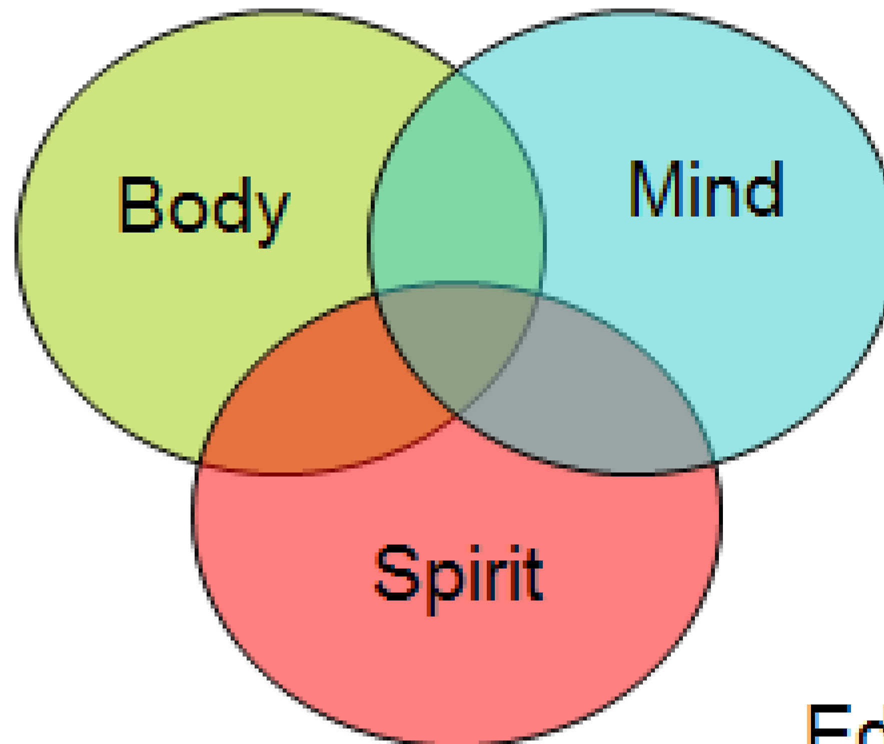


Personhood

Religion

Culture



Society

Education

What Are You Famous For?

WGYLM?

What Brings You Joy?

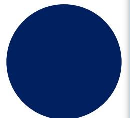
I AM…

What Would You Sacrifice Today for a *possible* Tomorrow?

Palliative Care:

- **Affirms Life**
  - **Supports patient/family goals for the future**
  - **Acknowledges hopes for cure or life prolongation as well as peace and dignity at time of death**
- **Does Not Hasten Death**
  - **Not PAS or Euthanasia**
- May Prolong Life[1]
- Improves Quality Life
- Helps patient and family work toward achievable goals in whatever time they have remaining.

[1] Temel JS et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer, N Engl J Med 2010;363:733-42



Ethical and Religious Directives:

- The task of medicine is to care even when it cannot cure.
- The innate dignity of human life in all its dimensions is integral to the role of medicine.
- The use of life sustaining technology must be viewed in light of the Christian meaning of life, suffering, and death.
- Two extremes are avoided: either the insistence on useless or burdensome technology even when a patient may legitimately wish to forgo it and, the withdrawal of technology with the intention of causing death.

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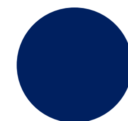

ERD 55

- Catholic health care institutions offering care to persons in danger of death…should (ensure) that patients be provided with whatever information is necessary to help them understand their condition and have the opportunity to discuss their condition with their family members and care providers.
- They should also be offered the appropriate medical information that would make it possible to address the morally legitimate choices available to them.
- They should be provided the spiritual support as well as the opportunity to receive the sacraments in order to prepare well for death

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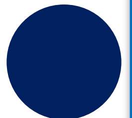

ERD 56

- A person has a moral obligation to use ordinary or proportionate means of preserving his or her life.
  - **Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.**

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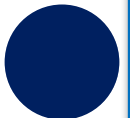

ERD 57

- A person may forgo extraordinary or disproportionate means of preserving life.
  - **Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.**

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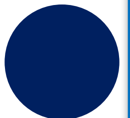
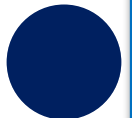


ERD 59

- The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching



ERD 61

- Patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in the place where they wish to die.
  - **Medicines capable of alleviating or suppressing pain may be given to a dying person, even if this therapy may indirectly shorten the person's life so long as the intent is not to hasten death.**

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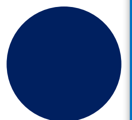

Barriers to Hospice & Palliative Care:

- Mistaken belief that there is "nothing more" to offer a dying patient
- Widespread perception that a patient's death is due to physician failure
- Clinicians worry that palliative care and hospice is tantamount to "giving up".
  - **Many believe that patients do not want to talk about death and dying.**
- Pts/families reluctant to seek or accept palliative care as they equate it with "giving up"
  - **Often lack understanding of benefits of palliative care and hospice.**

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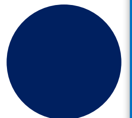
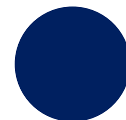


To Cure Sometimes…

To Relieve Often…

To Comfort Always.



Hospice – Origin and Definition

- Term hospice, from same linguistic root as "hospitality", can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey.

- Defined as: Team oriented approach to medical care, symptom management, and emotional and spiritual support tailored to the needs of a patient with a **terminal illness or injury**.

- Eligibility for Medicare Benefit: Patient is eligible for hospice care if two MD's (One should be a Hospice MD) determine the patient has a prognosis of six months or less.

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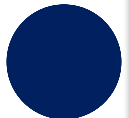

Further Definition of Palliative & Hospice Care

- Both Palliative Care and Hospice Care provide symptom management, enhance quality of life and respect patient's desires and preferences. Hospice care is specifically devoted to **End of Life care**.

- So, **ALL** Hospice Care is also Palliative Care, but **NOT ALL** Palliative Care is also Hospice Care.

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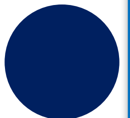
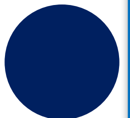


Terms NOT seen in the definition of Hospice Care

- Reduce Care
- Withhold Therapy
- Euthanasia
- Morphine Drip
- Death Squad
- Take Away Hope



Hospice Care: Where?

The majority of hospice care is provided in the place the patient calls home. This may include not only private residences, but also nursing homes and residential facilities. Hospice care may also be provided in freestanding dedicated hospice facilities and hospitals.

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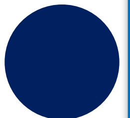
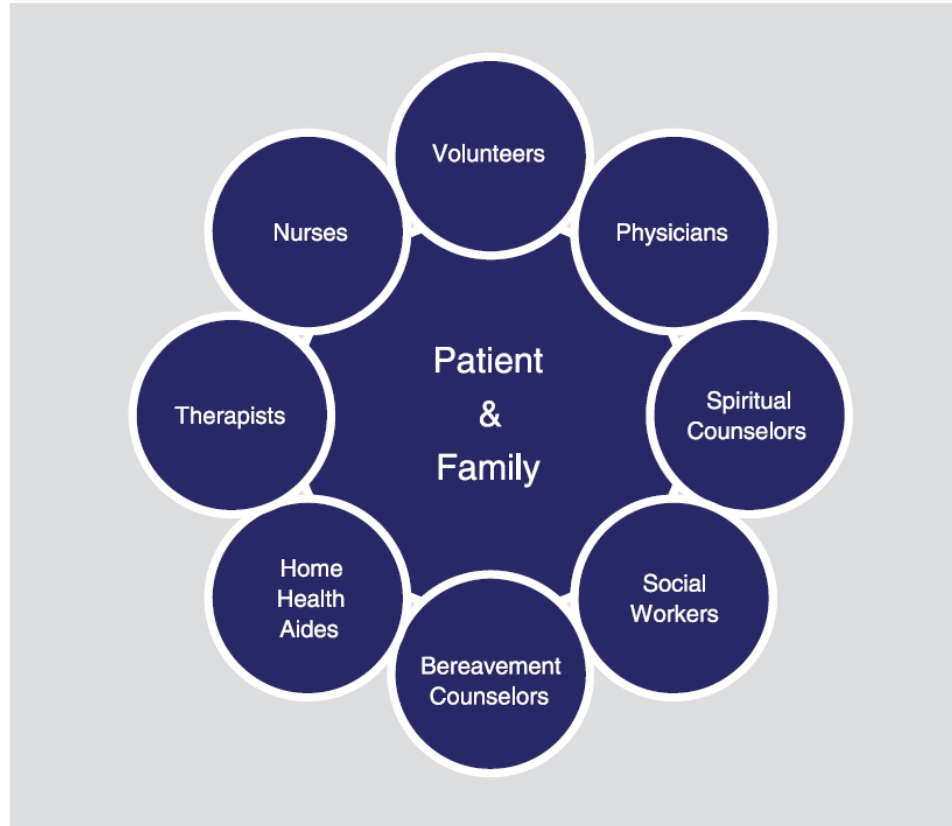


How Hospice Care is Delivered



Hospice Care is truly a team sport

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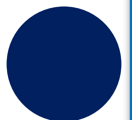
Source: NHPCO Facts & Figures – 2017 Edition



Volunteer Services

- U.S. Hospice Movement was founded by Volunteers
- Medicare requires volunteers provide at least 5% of all patient care hours
- Services provided:
  - Spending time with patients and families
  - Clerical services and other support
  - Other activities including: Fundraising, outreach, education

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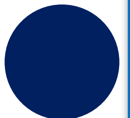

Hospice Levels of Care

GIP (General Inpatient)
- Approx. 1.5% of pts. nationally
- Uncontrollable symptoms
- Covered by Medicare Benefit

Respite
- Approx. 0.5% of pts. nationally
- Care giver fatigue
- Covered by Medicare Benefit

Routine
- Approx. 98% of pts. nationally
- No other viable options
- Room and Board is **NOT** covered

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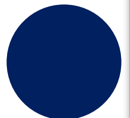

Hospice Statistics

- 1.43 million Medicare beneficiaries were enrolled in hospice in 2016

- 48% of all Medicare decedents were enrolled in hospice at time of death in 2016

- Proportion of Medicare decedents enrolled in hospice varied greatly from state to state
  - Highest: Utah, Arizona, Florida, Iowa
  - Lowest: Alaska, North Dakota, Wyoming

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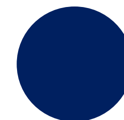

Hospice Statistics (Continued)

Diagnoses

– Cancer	27.2%
– Cardiac, Circulatory	18.7%
– Dementia	18%
– Respiratory	11%
– Stroke	9.5%
– Other	15.6%

Length of Service

- Average 71 days
- Median 24 days

Location of Deaths for Hospice Patients

– Home	44.6%
– Nursing Facility	32.8%
– Hospice Facility	14.6%
– Acute Care	7.4%

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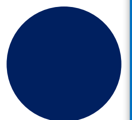

Franciscan St. Francis Hospice House

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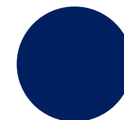

Advanced Care Planning

- **Advanced directives**-legal documents to ensure future health care choices are documented
- Laws often vary by state
- Gives every competent adult the right to make their own health care decisions including what treatment to accept, reject or discontinue as well as the right to name someone to make decisions for you

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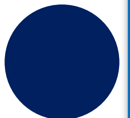

IN ADVANCED CARE DOCUMENTS:

- **Appointment of Health Care Representative**
- **Indiana POST Form**
- Out of Hospital Do Not Resuscitate Declaration
- Talking directly to your physician and family
- Living Will Declaration
- Organ and Tissue donation
- Psychiatric Advanced Directives
- Power of Attorney
  - Typically financial document, though can be both if “Durable Medical Power of Attorney”

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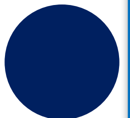

IN HEALTH CARE REPRESENTATIVE:

- Legal document that allows you to appoint another person as a representative to make health care decisions on your behalf
- Only takes effect if you should be temporarily or permanently unable to make those decisions yourself
- It is critical that the decision maker
  - Is aware of your wishes
  - Acts in your best interest

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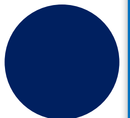

New Ranking Order for Decision Makers (effective 7/1/2018):

1. A Judicially appointed health care representative
2. A spouse; if no spouse, then
3. An adult child; if no adult child, then
4. A parent; if no parent, then
5. An adult sibling; if no adult sibling, then
6. A grandparent; if no grandparent, then
7. An adult grandchild; if no adult grandchild, then
8. The nearest other adult relative in the next degree of kinship (think aunts, uncles, nieces, nephews and cousins); if no other adult relative, then
9. A friend who is an adult, and has maintained regular contact with the individual, and is familiar with the individual's activities, health and religious or moral beliefs
10. If no friend, then the individual's religious superior if the individual is a member of a religious order.

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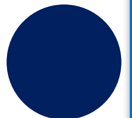

Indiana POST Form:

- Law enacted July 1, 2013, updated 2016.
- Physician Orders for Scope of Therapy-order set that can follow the patient in any care setting
- Appropriate in the following conditions:
  - Advanced chronic progressive illness
  - Advanced chronic progressive frailty
  - Any condition when the patient might be expected to die "in the near future" (i.e. 1-2 years)
  - Condition that leaves the patient unable or unlikely to benefit from resuscitation in the event of cardiac or pulmonary failure.

www.indianapost.org

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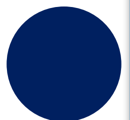

Do Not Resuscitate/Allow Natural Death

- Important to know statistics to make informed decision regarding DNR
- Since its invention in 1959, we have not significantly improved outcomes from CPR
- In general, survival to discharge for cardiopulmonary arrest is 15%
  - Worse when patients are older (>70yo), and/or has advanced disease (cancer, heart or lung disease, frailty)
    - **Survival is essentially 0 for those patients.**

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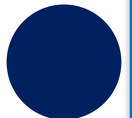
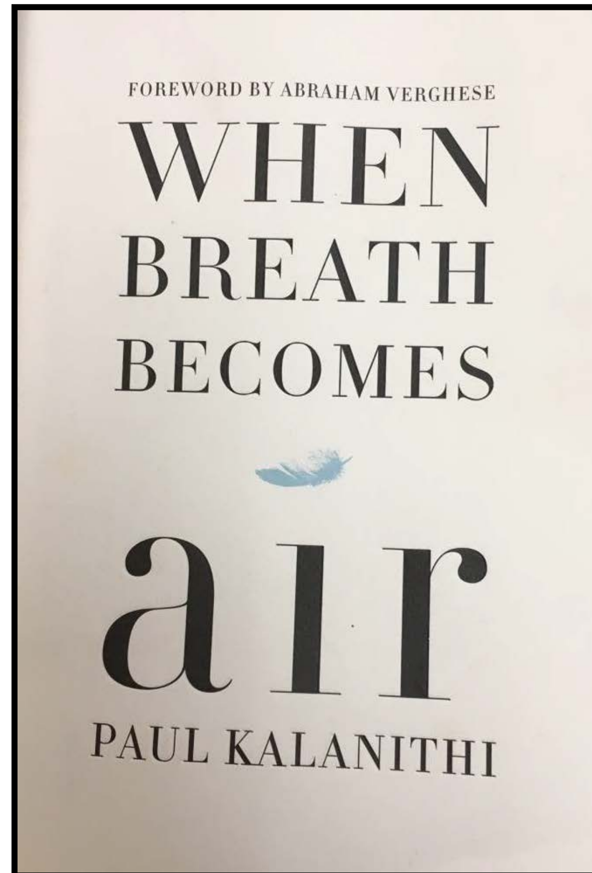
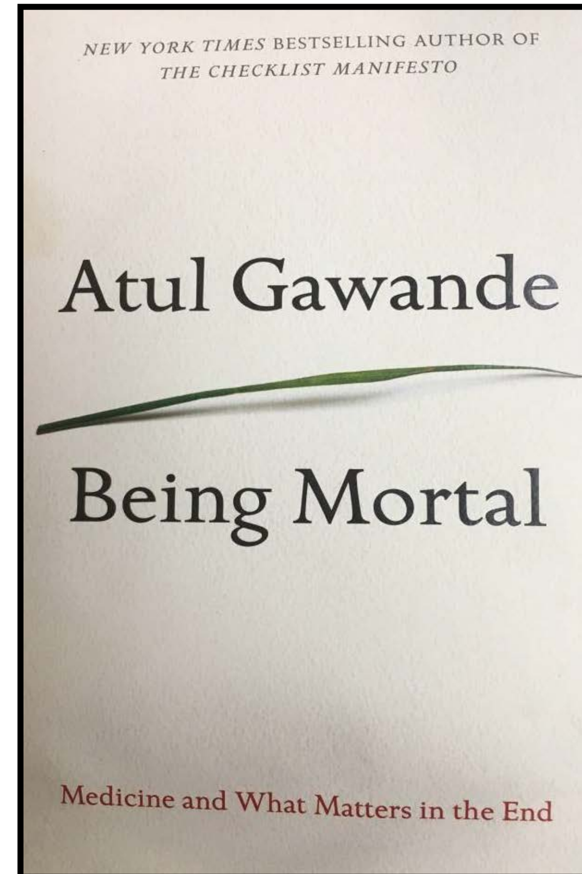


Reading References





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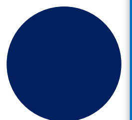

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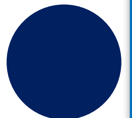

Comments and Questions?

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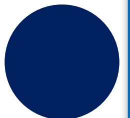

Parishioner: Casey

- 33 year old, married, 3 children at your elementary school.
- Diagnosed with Melanoma (a very serious skin cancer- can be treated, potentially cured if caught early, however quite lethal if caught late, or after it has spread.
- Asked to speak with you about this diagnosis, and its impact.

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