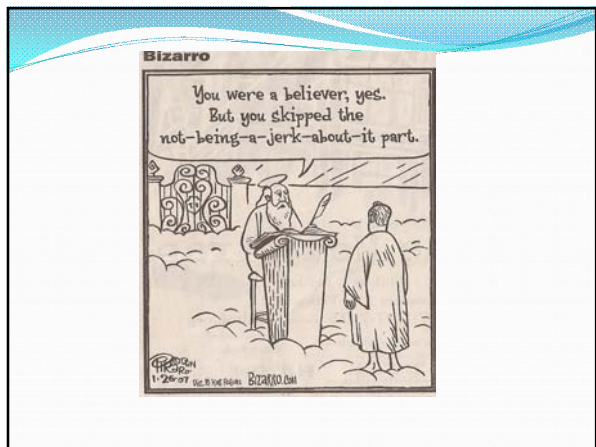


## Palliative Care Across the Lifespan

Peter Jupin  
Staff Chaplain  
Lancaster General Health

### What is Palliative Care?

- A philosophy of care (a way of thinking) and a structured approach (a way of doing)
- Patient-centered care with a focus on preventing and relieving suffering and on enhancing the quality of life for patients and families
- Relationship-Based Care
- Care throughout the continuum of an illness, from diagnosis to death and beyond.



### Focus

- Pain management
- Management of distressing symptoms: SOB, fatigue, discomfort, constipation, nausea, anorexia, sleeplessness
- Comfort
- Goals of Care
- Advance Planning / Advance Directives
- Decision-making
- Quality of Life
- To give patients and families the capacity to realize their full potential

### Philosophy

- Affirms Life and Affirms Death
- Body - Mind – Spirit Integration

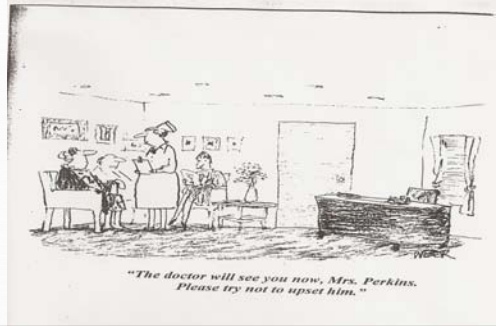
### Preferred Practices

- Interdisciplinary Team
- Communication
- Flexible / Adaptable Care Plan
- Responsiveness
- Continuity of Care
- Education of medical staff and community
- Bereavement
- Continuing Education.

## Ethical Concerns

- **Autonomy:** Who is decision-maker?  
What voice does family have?
- **Beneficence:** What is good for the patient? Family?
- **Non-maleficence**
- **Justice:** What is fair?
- Benefit v. Burden
- What is "quality of life"?
- Cultural Factors
- Staff Moral Distress

## The Medical Model



*"The doctor will see you now, Mrs. Perkins.  
Please try not to upset him."*

## Pain

- Fear of addiction
- If pain treated early, no options for future pain
- Anxiety about unpleasant side effects
- Fear that increasing pain = disease progression
- Desire to be "good" patient.
- Concern about high cost of meds

## Emotional, Psychological, Behavioral Dimensions of Palliative Care (PC)

- Stress
- Anger, fear, anxiety, depression
- Loss of / inadequate coping skills
- Loss of function, identity
- Dependency, helplessness
- Cognitive impairment, dementia
- Grief

## Spiritual Dimensions of PC

- Spirituality v. Religion
- Existential Concerns: Despair, search for meaning and purpose
- Relationships, Forgiveness, Reconciliation
- Suffering and Abandonment
- Guilt / Shame

## Spiritual Dimensions of PC

- Beliefs, Values, Priorities
- Images of God
- Death / Afterlife
- Saying Good-Bye



## Final Challenges

- Challenge 1: Summing up the past as final chapter in my autobiography. What have I done? How did I live? What is my legacy?
- Challenge 2: Making a final statement about my future, my last days. What do I still want or need? What am I able to do? What unfinished business do I have?



## End of Life Interventions

- Privacy, uninterrupted time together
- Make sure family understands signs and symptoms of imminent death.
- Offer anticipatory bereavement support.
- Children?
- Ritual, prayer, scripture
- Be a presence in the room.

## Maxims of Palliative Medicine

J. A. Probolus M.D.

- Meet people where they are and then walk with them.
- Most people are reasonable people put in difficult circumstances.
- Not everything can be or even should be accomplished on an initial visit.
- Time spent building rapport is rarely wasted.

## Maxims

J. A. Probolus M.D.

- To alleviate suffering, you must first identify it.
- To identify suffering, you must hear the story, as told by the sufferer.
- When you do not know what to do, ask more questions.
- When you do not know what to say, stay silent and bear witness.

## Maxims

J.A. Probolus M.D.

- When in doubt, get everyone together and talk about it.
- Thou shalt not pile drive the plan of care.
- This is not about you; if it starts to be, ask for help.
- Be the change you want to see in institutional culture.

## Final Gifts

The Four Most Important Things, Ira Byock M.D.

- Please forgive me.
- I forgive you.
- Thank you.
- I love you.

