

# Palliative Care, Hospice and Last Resort Options: *Facing an Uncertain Future Together*

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# Potential Conflicts of Interest

*I have no significant financial conflicts of interest to disclose.*

*I have been and am a cautious advocate for more open access to "last resort" options including physician assisted death to address extremes of end of life suffering.*

# “Western” Culture

Much more diverse than is regularly acknowledged

Rugged individualism; personal choice

Truth-telling, with an emphasis toward the positive

- *Significant cultural and individual variation*

Death as an enemy rather than a natural part of the life cycle

Families smaller and more spread out

Little preventive care, but unlimited catastrophic care

Relatively little death talk

# Culture of Medicine

Deification of technology

Death as a medical failure, giving up

- *Do not go gently into the night; rage, rage against the light*
- Physicians as patients often accept much less aggressive treatment

Limits of medicine vs. limits of your doctor or system

Truth telling, but shading toward the positive/hopeful

Costs are disconnected from outcomes or social norms

# Background Data: Palliative Care

Inadequate pain and symptom management

Inadequate physician training in palliative care

Economic incentives promote over-treatment

Physicians overly optimistic prognostication

30-35% completion of advance directives

Medical rituals replacing religious rituals

Infrequent, very late referrals to hospice

# Healing Approaches to Serious Illness

## Limits of usual conceptualization

- Curative or restorative disease-based model
- Unclear how adaptation to chronic illness fits
- Death as a medical failure

## Broader model of healing

- Maintaining integration and wholeness
- Finding meaning and maintaining connection
- Opportunity for growth and closure
- Commitment to face the unknown together

# Palliative Care and Hospice

## Definition of Terms

Palliative Care: biopsychosocial and spiritual care of persons whose diseases are not responsive to curative treatment

Goal of Palliative Care: to produce the best possible quality of life for the patient and family

Hospice: Medicare sponsored program dedicated to provide palliative care for terminally ill patients and their families

# Elements of Medicare Hospice Benefit

“Cadillac” of home care programs

Payment for all medications and medical services

Expert team of experienced caregivers

Supplementation of care at home or nursing home

Option of respite care and emergency inpatient care



# Elements of Medicare Hospice Benefit

Capitated, per-diem reimbursement

Prognosis of 6 months or less

Waive rights to curative treatment

Primary care giver – not 24 hour care

# Limitations of Medicare Hospice Benefit

Inherent prognostic uncertainty; late referrals

Largely restricted to cancer patients in the past

Criteria developed for very advanced dementia, CHF, COPD, frailty,...

Unavailable to those who want to continue active Rx

Primary care giver requirement

Cultural, ethnic, socioeconomic barriers

# Some Challenges of the Discussion About Hospice

Hospice requires a “bad news” discussion

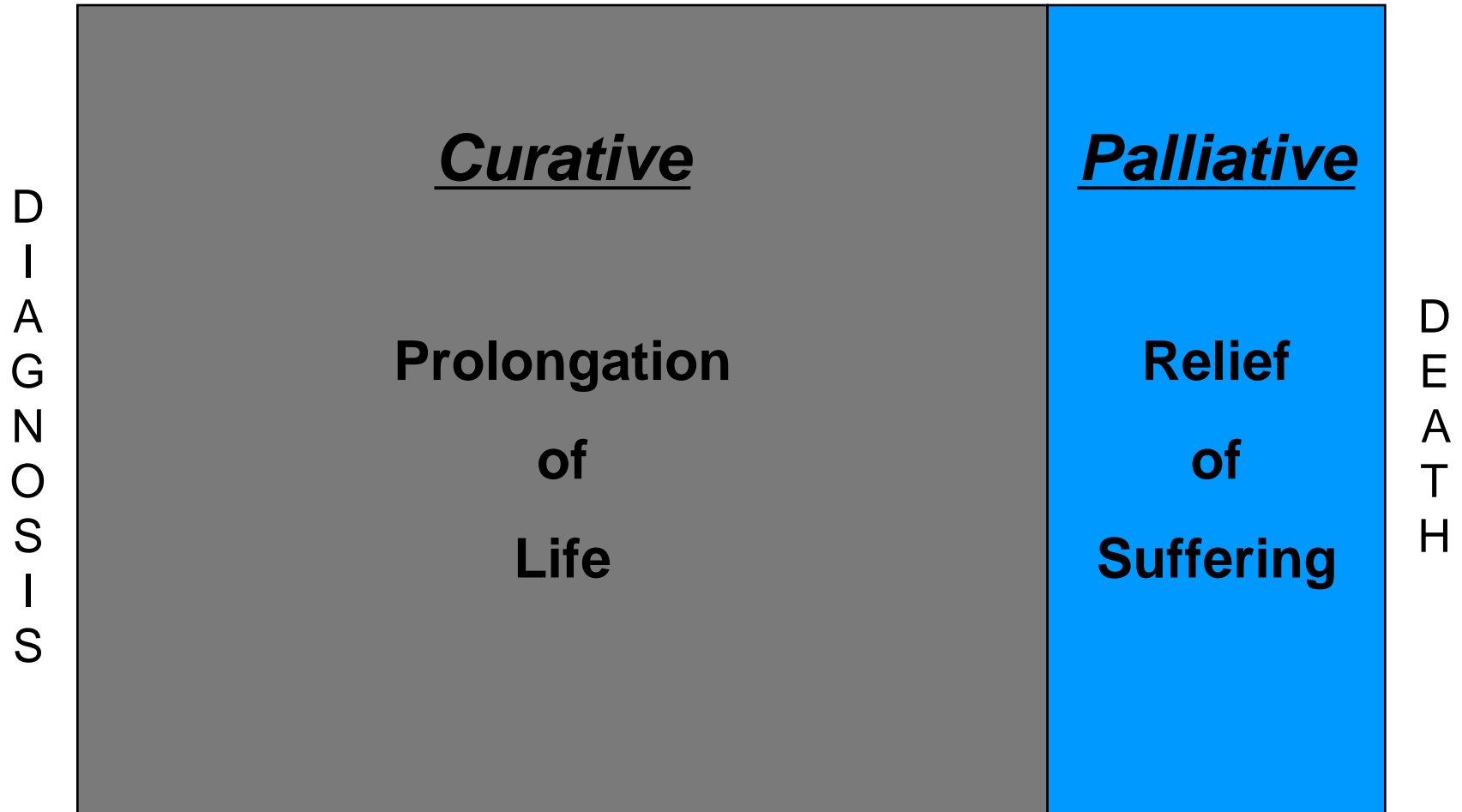
- Acceptance that medical treatment isn’t working
- Acceptance of likelihood of death in 6 months
- Giving up on hospitalization and disease-driven treatment

Many patients don’t want to stop all treatment

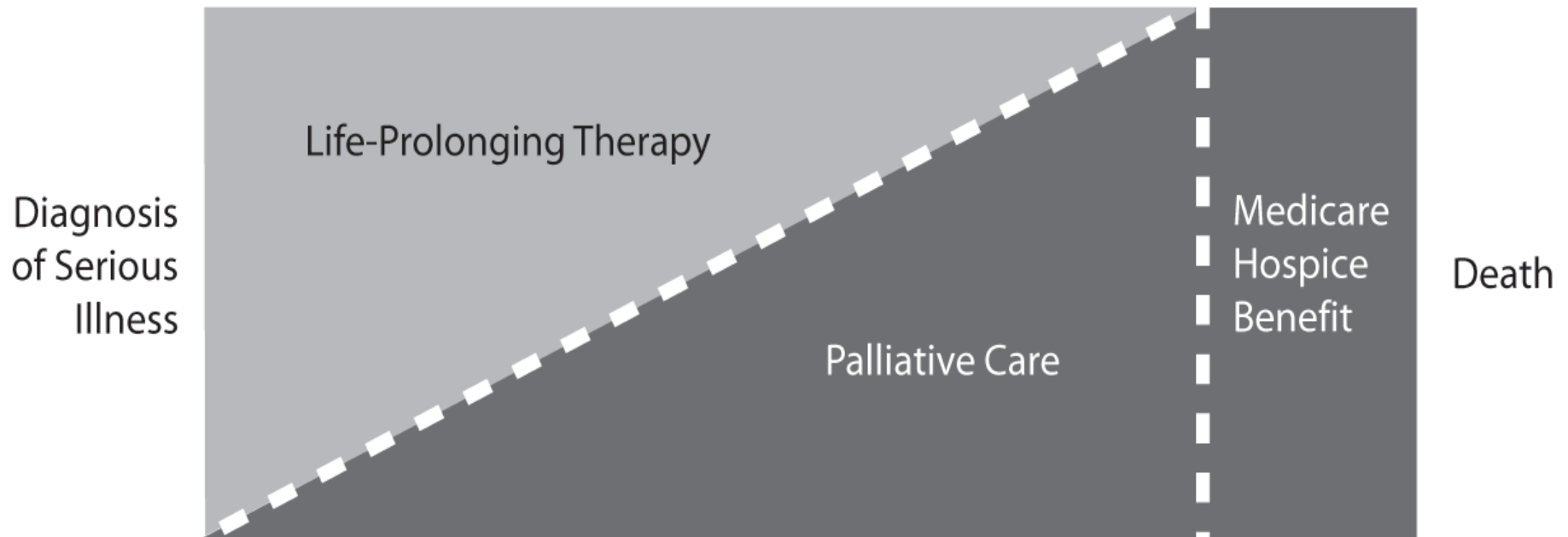
- May be willing to stop burdensome treatment
- May want to continue to maintain more options

Small chances of cure or longer life maintain hope

# END-OF-LIFE CARE TRANSITION TO HOSPICE



# As illness progresses, an increasing emphasis on palliation...



# Palliative Care ~~=~~ End of Life Care

Communicating prognosis while maintaining hope

Making decisions about anti-cancer treatments, life support, cardiopulmonary resuscitation, substituted judgment, hospice

Exploring the full range of treatment options

Symptom reduction, physical and emotional functioning, spiritual well-being

# Palliative Care: *Hoping and Preparing*

*"Let's hope for the best..."*

- Join in the search for medical options
- Open exploration of improbable/ experimental Rx
- Ensure fully informed consent

*"...attend to the present..."*

- Make sure pain and physical symptoms are fully managed
- Attend to depression and any current psychosocial issues
- Maximize current quality of life

*"...and prepare for the worst."*

- Make sure affairs (financial/personal) are settled
- Think about unfinished business
- Open spiritual and existential issues

# Like hospice, palliative care provides:

Improved pain and symptom management

Careful attention to quality of life

Fresh look at medical goals and priorities

Opportunity to consider life closure

Multidisciplinary approach

Focus on patient and family



# Unlike hospice, palliative care does not require:

Forgo active treatment of underlying disease

Forgo acute hospitalization

Accept palliation as primary goal of treatment

Accept a 6-month or less prognosis

# When to discuss palliative care:

Would you be surprised if patient died this hospitalization?

- Patient imminently dying
- Significant suffering and poor prognosis

Would you be surprised if patient died in 6 months?

- Significant suffering regardless of prognosis
- Patients who fear future pain and suffering
- All patients with possibly life-threatening illness

# Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *NEJM. 2010;363:733-42*

- RCT of 151 patients with newly diagnoses metastatic non-small cell cancer
  - Standard oncologic care (SOC) alone
  - SOC plus early and ongoing palliative care PC (consult and monthly visits)
- Measures
  - Health related quality of life (FACT-L)
  - Mood (HADS and PHQ-9)
- Results – patients who received SOC plus PC had significantly
  - Better quality of life (FACT-L 98.0 vs 91.5;  $p=0.03$ )
  - Less depression (16% vs 38%;  $p=0.01$ )
  - Less aggressive medical care at end of life (33% vs 54%;  $p=0.05$ )
  - Longer median survival (11.6 vs 8.9 months;  $p=0.02$ )

# Specialty vs General Palliative Care

## General Palliative Care

- Provided by non-palliative specialist or primary care clinician
- May be alongside any and all other desired treatments
- Part of good medical care delivered by existing providers

## Specialty Palliative Care

- Provided by a clinician with specialty training in palliative care
- May also be alongside any and all other desired treatments
- May require more specialized knowledge and training
- Potentially be restricted to more difficult cases
- May be consultative or primary management

# Specialty vs General Palliative Care: Some clinical examples...

## General Palliative Care

- Basic pain and symptom management
- Goals of care discussions
- Family meetings for decision making
- Decisions about stopping treatment or resuscitation

## Specialty Palliative Care

- Complex pain and symptom management
- Major family conflict over plan of care
- Near futility discussions
- Accessing “last resort” options for refractory distress

# *Isn't palliative care just good medicine?*

Most clinicians have not been formally trained in the basics

- Not a regular part of medical school and residency training
- Practicing clinicians are largely self taught
- May not know what they don't know
- Knowledge and skill base uneven at best

Most non-specialists do not see the most challenging cases

- Refractory symptoms unresponsive to basic treatments
- Invasive symptom management measures
- Severe depression and hopelessness
- Wish to die

# *Some Difficult Questions*

*"Should I try experimental therapy?"*

*"Is it time for hospice?"*

*"How can hope be preserved?"*

*"Will you help me die if my suffering becomes unacceptable?"*

# ***Should I try experimental therapy?***

It might work!

Avoids the sense of “giving up”

Contributes to future knowledge

He has always been a fighter!



# ***Why not try experimental therapy?***

May medically define the last stage of life

May avoid important discussion and planning

Spend precious time in hospitals with doctors

More symptomatic from side effects

# Experimental Therapy: *Finding a Balance*

If it is non-toxic, why not? Explore the details

Explore the patient's values and preferences

Both hope and prepare

Not all miracles are medical

Share your experience and recommendations

# *Is it time for hospice?*

Goal is primarily palliation

- No acceptable disease treatment options available
- Experimental treatment not promising

Some serious advantages

- Much more support at home – 2-4 hours per day
- Payment for medications and durable goods
- Support of a multidisciplinary team
- Focus on patient and family
- 24 hour back-up at home

# *Is it time for hospice?*

But it is usually a hard transition...

- Disease treatment not working
- More likely than not to die in next 6 months
- Most likely forgo aggressive life prolonging therapy

Most patients and families very satisfied

- Intensive multidisciplinary focus on quality of life
- Care in one's own home if at all possible
- Good back up systems

# Preserving Hope

## Medical avenues of hope

- Breakthrough from traditional treatment
- New or experimental treatment
- Enhancing quality of life through palliative treatment

## Non-medical dimensions

- Spiritual or religious
- Family
- Alternative therapies
- New and different personal goals

# Palliative Options of Last Resort: Why are they important?

Reassurance for witnesses of bad death

Potential escape when suffering unacceptable

Awareness of potential options important to some patients,  
families, and caregivers

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# PALLIATIVE CARE

## Correctable Limitations

Limited access to care

Inadequate physician training

Barriers to pain management

Reimbursement disincentives

Palliative care offered too late

Physician lack of commitment

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# PALLIATIVE CARE

## Uncorrectable Limitations

False reassurance

Exceptions unacknowledged

Uncontrollable physical symptoms

Psychosocial, existential, spiritual suffering

Dependency, side effects

Devaluation of some patient choices

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# INTERLOCKING PUBLIC POLICY QUESTIONS

How to improve access to and delivery of palliative care services to all dying patients?

How to respond to those infrequent, but troubling patients who are dying badly in spite of excellent care?

Should we respond to individual cases or create public policy?

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# Reassurance about the future

Commitment to be guide and partner

Explore hopes and fears

- *What are you most afraid of?*
- *What might death look like?*

Commitment to face worst case scenario

Freedom to worry about other matters

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# What do Terminally Ill Patients Say? Considering versus Pursuing PAD

988 terminally ill outpatients (except AIDS)

- 60% support PAD
- 10% seriously considering PAD

92 terminally ill inpatients (Calvary hospice)

- 17% had a high desire for PAD

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Emanuel, Breitbart, Tolle



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# Will You Help Me Die?

Full exploration; Why now?

Potential meaning of the request

- Uncontrolled symptoms
- Psychosocial problem
- Spiritual crisis
- Depression, anxiety

Potential uncontrolled, intolerable suffering

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# Will You Help Me Die?

Insure palliative care alternative exhausted

Search for the least harmful alternative

Respect for the values of major participants

Patient informed consent

Full participation of immediate family

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# Potential Last Resort Options

Accelerating opioids to sedation for pain

Stopping life-sustaining therapy

Voluntarily stopping eating and drinking

Palliative sedation

Physician-assisted death

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# Accelerating Opioids for Pain

## *Main Elements*

Opioids mainstay in severe pain management

Dose is proportionate to level of pain

Small risk of sedation, respiratory depression, death with very high doses or sudden change

Risk is minimal in usual pain management

Death, if it comes, is unintended

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# Stopping Life-Sustaining Therapy

## *Main Elements*

Potentially life-sustaining Rx include:

- Mechanical ventilation
- Renal dialysis
- Feeding tube; intravenous fluids
- Implantable defibrillator
- Steroids; usual disease-treating measures

May be withheld, or withdrawn once started

Decision-making by patient if capable, or by family if incapacitated (*based on substituted judgment*)

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# VOLUNTARILY STOPPING EATING AND DRINKING

## *Main Elements*

Result of active patient decision

Patient physically capable of eating

Requires considerable patient resolve

Takes one to two weeks

Theoretically does not require physician involvement

Symptom management as process unfolds

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# PALLIATIVE SEDATION

## *Main Elements*

Sedation potentially to unconsciousness, life-supports withheld

Uses benzodiazepines or barbiturates

Process usually takes days to weeks

Patient dies of dehydration or complication

Patient unaware of suffering

Combination of “double effect” and withholding life-sustaining therapy

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# PHYSICIAN-ASSISTED DEATH

## *Main Elements*

Physician provides means at patient's request

Patient must carry out final act

Potential escape is important to many

Physician moral responsibility as an accomplice

Synonyms include:

- *physician-assisted suicide*
- *physician aid-in-dying*

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# Some Data from Oregon

(Tolle S et. Al. J Clin Ethics.2004;15:111-8)

1/500 deaths by PAD

1/50 talk with their doctor

1/6 talk to their families

*MOST PEOPLE WANT TO TALK*

*VERY FEW ULTIMATELY ACT*

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# Physician Assisted Death in US: Legalization in Four States

Oregon by referendum

Washington State also by referendum

Montana by constitutional challenge

Vermont by legislative action

(California also by legislative action now awaiting governor signature)

(New Mexico currently in flux)

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# Physician Assisted Death in Canada: 2015

## Canadian Supreme Court

- Fundamental Right to choose physician assisted death
- Potentially includes either PAD or VAE

## Criteria included

- “Grievous and irremediable medical condition...”
- “Causes enduring suffering that is intolerable to the individual”

12 months to enact a regulatory framework (February 2016)

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# PALLIATIVE OPTIONS OF LAST RESORT

## *The Need for Safeguards*

Protect vulnerable from error, abuse, coercion

Ensure access and adequacy of palliative care

Risks cited for PAS are also present for other last resort options

Balance flexibility and accountability

Balance privacy and oversight

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# PALLIATIVE OPTIONS OF LAST RESORT

## *Categories of Safeguards*

Palliative care accessible and found to be ineffective

Rigorous informed consent

Diagnostic and prognostic clarity

Independent second opinion

Documentation and review

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# Risks of “*Don’t Ask, Don’t Tell*” Policy

Access uneven and unpredictable

Discourages explicit conversation

Risk of misunderstanding

No safeguards to ensure adequate palliative care and adequacy of evaluation

Potential bereavement problems with secrecy

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# Advantages of Being Explicit about Last Resort Options

Acknowledges the problem

- Less patient and family fear
- Free energy for other more important tasks

Reinforces the physician imperative to be responsive

- Nonabandonment
- Get help if you need it!

In Oregon, most patients want to talk; very few act.

- 1/1000 die using PAS
- 1/50 talk to their doctor
- 1/6 talk to their families

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# Potential Risks of Being Explicit about Last Resort Options

Might frighten some patients

Might lead to pressure to prematurely choose death

- Family pressure
- Financial pressure

Might undermine progress in hospice and palliative care

- Lessen commitment to address difficult suffering
- An easy out as suffering increases

Might undermine fundamental physician values

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# Palliative Care The Bottom Line

Palliative care should be part of the plan for all seriously ill patients

- *Don't wait for it until there is a drastic need!*

All clinicians who care for seriously ill patients should know how to do basic palliative care

Specialist palliative care backup is available to help manage more difficult symptoms and help with more challenging decision-making

Challenge is to use medicine's full potential in an individualized way

# Hospice

## The Bottom Line

The premiere program providing palliative care for terminally ill patients and their families

Very hard transition for many patients and families

Yet most are very appreciative once transition is made

More help at home than any other home care program; can also be provided in nursing homes and hospice houses

Most patients can find a meaningful and relatively peaceful death on hospice, but there still may be challenges

# PALLIATIVE OPTIONS OF LAST RESORT

## *The Bottom Line*

Only sensible in context of excellent palliative care

Currently, options unevenly / unpredictably available

All options should be subject to similar safeguards

Open processes are ultimately more safe, predictable, and accountable than secret processes

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# Case Introduction

35 y.o. grad student; religion and psych

Buddhist: connection, consciousness, quality

Very healthy

Upper abdominal pain

No nausea, vomiting, bowel changes, blood

No HIV risks, drugs, ETOH, NSAIDS

Initial physical examination normal

# Continuation of Case

## History

- No response to antacids
- Early satiety; unable to eat full meals
- Lost 5 pounds
- No vomiting, blood; few bowel movements

## Physical examination

- Fullness and probable mass in epigastrium
- Stool guaiac negative



# What kinds of cancer can produce this picture?

## Likely possibilities

- Lymphoma
- Gastric cancer

## Rare possibilities

- Benign tumors of stomach wall muscle
- Carcinoid cancer
- Sarcoma; leiomyosarcoma

# Summary Facts about Gastric Cancer

90-95% of stomach malignancies

Decreasing incidence over 40-50 years

Common in Japan, Eastern Europe, Finland

Relationship to chronic H. Pylori infection, smoked food, nitosamines, familial polyposis

Male/female-2/1; rare under age 40

5 year survival 5-15%

*Linitis plastica*; Signet cells=>poor prognosis

# Which experimental protocol was available?

Total gastrectomy; esophagojejunostomy

Feeding jejunostomy; central intravenous line

Intraperitoneal mediport for chemotherapy

Combination chemotherapy (5 FU, VP 16, Cisplatin, adriamycin, mitomycin C)

# Cynthia wanted other assurances about her care.

Stop experimental therapy if too hard

Relieving uncontrolled pain

Relieve mental confusion and anguish

Help her die if dying became too harsh

# Findings at Surgery

Poorly differentiated, infiltrative adenocarcinoma

Signet cells; transmural invasion

12/12 lymph nodes positive lesser curvature; 12/16 positive greater curvature

Margins grossly free of tumor

No obvious liver metastases

Ascitic fluid positive for tumor

# Clinical Course After Initial Surgery and Chemotherapy

Surgical recovery and chemo very harsh

Good pain control with PCA infusion pump

Poor control of nausea and vomiting

Multiple surgeries for bowel obstruction

Progressive weight loss

No response to chemotherapy

# Hospice now had a very different meaning.

Transforming effect of a month in hospital

Pain and symptom management

- Pain well controlled with PCA infusion
- Nausea and vomiting - aggravated by chemo
- Open wounds - local treatment

Psychosocial and Spiritual Preparation

- Live as long as there was quality; die peacefully
- Prepare for death

# Cynthia had a wonderful month at home on hospice.

Reasonably good pain and symptom relief

Able to walk around at first; beautiful setting

Parents moved to town to be near her

Married her long-term boyfriend

Group meditation with Buddhist community

Gave away her favorite possessions

Prepared herself for death



# Eventually, palliative efforts became less effective.

Tradeoffs between pain and sedation

Constant nausea/vomiting despite treatment

Smell of wounds and vomitus humiliating

Too weak and tired for quality interaction

Had achieved a peace with death, and was prepared

# Before making any irreversible decision that might end in her death, what should we check?

Are we fully addressing her pain and symptoms?

Are there financial, social, family, spiritual issues?

Is she thinking clearly (depression or delirium)?

Is the decision consistent with past values?

# Cynthia's Decision

Open discussion with her and family

Stopping artificial fluids and gradually increasing opioids was acceptable

Brief euphoria after stopping fluids

Gradually went into a coma over 48 hours

Died peacefully with family and friends in attendance

# Using Medicine in an Individualized Way

Privilege to work with patients like Cynthia

Make best possible decisions in the face of tragedy

Importance of honest/humane communication

May have to talk about death and dying while fighting vigorously for life

Always keeping the values of the patient and family in the forefront of medical decisions

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