MASS PI MASSACHUSETTS PAIN INITIATIVE

Massachusetts Pain Initiative Spring 2018 Conference

Compassionate Care in the Millennium

Friday, March 16, 2018

Holiday Inn Hotel & Suites, 265 Lakeside Avenue, Marlborough, MA
Registration and Breakfast: 8:00 a.m. – 8:30 a.m.
Meeting: 8:30 a.m. - 3:30 p.m.
Breakfast and lunch provided

Program Schedule

8:00 a.m. - 8:30 a.m.	Registration/continental breakfast
8:30 a.m. - 9:00 a.m.	Welcome and council report
9:00 a.m. - 11:00 a.m.	***Dr. M.R. Rajagopal and film viewing: Hippocratic: 18 Experiments in Gently Shaking the World***
11:00 a.m. - 11:20 a.m.	Break and visit vendors
11:20 a.m. - 12:15 a.m.	***Continue discussion of the film and compassionate care issues***
12:15 p.m. - 1:00 p.m.	Lunch and visit vendors
1:00 p.m. - 3:00 p.m.	***Dr. Jennifer Ritzau***
3:00 p.m. - 3:30 p.m.	Q&A/closing

Speakers

Dr. Rajagopal is a 2018 Peace Prize nominee and global health thought leader. He is a world-renowned expert in pain management and palliative care. He is the founder of the Pain and Palliative Care Society in Calicut, India which has grown over the last ten years into the largest palliative care center in the country. He works tirelessly to improve opioid availability in India.

Dr. Jennifer Ritzau, director of palliative care and associate medical director at Hope Hospice, leads a team of physicians, nurse practitioners and physician assistants providing palliative care across a continuum that stretches from hospitals to long term care. In addition, as medical director of Visiting Nurse of HopeHealth, she directs their palliative care team, providing an extra layer of support for skilled home care patients living with advanced illness.

Introducing Dr Rajagopal and *Hippocratic - 18 Experiments in Gently Shaking the World*

Hippocratic is a feature-length documentary which follows the story of Dr MR Rajagopal in his journey to deliver compassionate palliative care to India.

Described by the *New York Times* as 'the father of palliative care in India', recipient of the Human Rights Watch's Alison Des Forges Award for Extraordinary Activism and nominated for the 2018 Nobel Peace Prize, Dr Raj is an incredible source of wisdom and inspiration.

The Indian physician's mission is to see modern medicine adopt whole-person, ethical care by providing universal access to essential and heavily restricted pain medications.

In a country where one-third of all poverty is caused by disease and its treatment, Dr Raj seeks to stop the medical system from fuelling the poverty endemic.

Drawing upon the teachings of Mahatma Gandhi and combining these with Dr Raj's personal experiences results in a powerful biographical film that explores the strength of the human spirit, human rights, global health care and social justice.

"The Hippocratic Oath asks me to treat my patients with warmth, sympathy and understanding. Once we are able to practice it, we are able to make the Hippocratic Oath come alive – it doesn't live until then."

Dr Raj's story reveals both the challenges and successes of changing the world through ethical and humane palliative care.

US Speaking Tour

Following the success of the Australian Speaking Tour for the release of Hippocratic, as well as screenings in New Zealand, Asia and Eastern Europe, a tour of the United States has been proposed for March and April 2018.

The US Speaking Tours will feature an introduction and Q&A session by Dr Raj as well as a screening of the film.

This presents an outstanding opportunity to welcome a globally acclaimed health professional and leader in palliative care to your city, workplace or organisation.

Speaking Tours facilitate knowledge sharing, fundraising and media exposure. They are an opportunity to start a conversation about palliative care and to raise awareness of your organisation, it's role and it's values.

Australian Speaking Tour

The Australian Speaking Tour saw Dr Raj welcomed into venues such as universities, hospitals, departments of medicine, schools of global population health and Australia's leading cancer centre.

Palliative care organisation, study centres, facilities, Indian-Australian medical groups, individual activists and community groups alike were eager to host screening events.

As a result, we saw a significant fundraising effort around the country and mainstream media engagement with the project. The Speaking Tour received fantastic feedback from hosts of the event who said the audience expressed their inspiration, emotion and concern for the issues raised within the film.

Find Out More

A Hippocratic screening event highlights the importance of universal access to health care and pain management services. Set in India where not everyone has universal access to pain management, the film presents the individuals tirelessly working towards a compassionate, ethical, and accessible system.

The film explores the link between health and poverty. It challenges the medical system consider the ethics of health care and to provide treatment to all those who need it.

In America where opioid deaths are a topical issue, Hippocratic presents a timely exploration of the intricacies of facilitating the legitimate and responsible use of opioids while constructively managing the challenges and debate surrounding the issue.

Hospice and Palliative Care Adding Value in Health Care

Jennifer Ritzau, MD
Massachusetts Pain Initiative
March 16, 2018

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Cure sometimes, treat often, comfort always.

-Hippocrates

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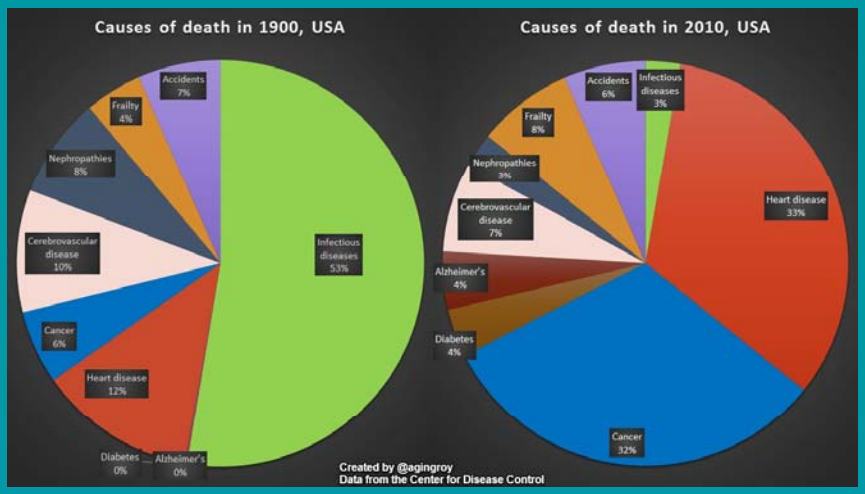

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History of Hospice

- 11th Century Monasteries "hospice" place of comfort and care for wounded or ill travelers, root of word "hospitality"
- 1950s-60s saw much advancement with critical care, ICUS but patients we still dying…many with unmet needs *"suffering"*
- 1967 St Christopher's Hospice Founded London
- 1974 Branford Hospice (CT) Florence Wald, RN
- 1974 Medicare Offers payment for hospice services…and the Regulations Begin
- 1977 Home and Hospice Care of RI – 2nd oldest in US

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Hospice is….

- Caring for more than 1.65 million Americans, and their families, every year—
- Utilization continuing to grow
- focused in on caring, not curing.
- an interdisciplinary team of healthcare professionals and trained volunteers that address symptom control, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.

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Hospice is Not…

- Giving up…Assisted suicide…Euthanasia
- Limited to 6 months- do not confuse eligibility with duration of services
- "irreversible" –families can change their mind at any time and seek curative treatment
- "a good death with morphine"- some of our patients never use any morphine
- Limited to patients who are CMO- can be FULL CODE

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High Quality, Patient Centered

- Nine in ten adults (88%) would prefer to die in their homes, free of pain, surrounded by family and loved ones [1]
- 94% of families who had a loved one cared for by hospice rated the care as very good to excellent[2]
- Expanding the reach of hospice care holds enormous potential benefits for those nearing the end of life, whether they are in nursing homes, their own homes, or in hospitals [3]

So what is the problem??

[1] gallup poll
[2] National Hospice and Palliative Care Organization
[3] US Dept Health and Human Services

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"Don't freak out—it's just a save-the-date."

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What is Palliative Care?

- Specialized medical care for patients living with serious illness
- An added layer of support to patient and family
- Works with existing health care team to clarify understanding of illness, discuss prognosis, complete advance care planning and manage burdensome symptoms
- Addresses "Whole patient" emotional spiritual physical, psychological in context of "family"

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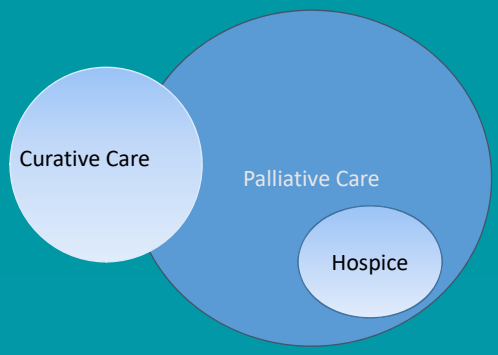
For the Mathematicians…



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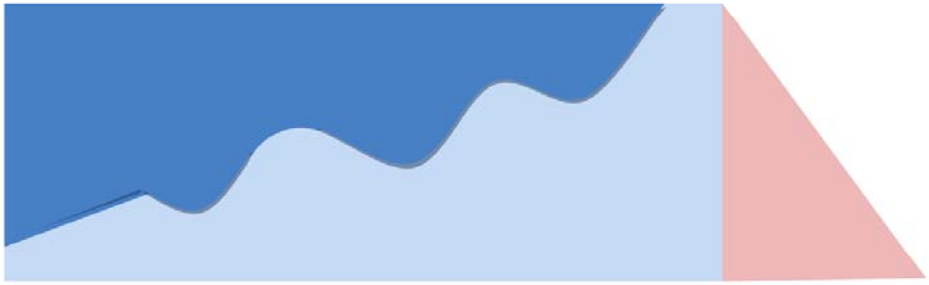
I Have a Dream…

Disease-Directed Therapies



Diagnosis **Palliative Care** **Death and Bereavement**

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What do we do?

- Symptom management
- Goals for care discussions
- Advance Directives
- Delivering serious news
- Addressing emotional and spiritual needs
- Assist with prognostication
- Assisting with transitions in care

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Good News

- Inpatient palliative care now is in 94% hospitals with >300 beds, achieving a penetration of 4.8% of all inpt admissions
- Growth continues especially inpatient where cost savings are easy to show
- Palliative Care Report card, RI gets an A for 80% hospitals offering inpt palliative care

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CAPC National Palliative Care Registry Data

More Good News- High Quality

- Improved quality of life
- Improved patient and team satisfaction
- Diminished caregiver distress
- Improve symptom burden
- Increase in advance care planning
- Improvement in survival

Irwin et al Chron Respir Dis 2012; 10(1) 35-47
Glare P JNCCN 2013:11 (supp 1):s3-9
Casarett et al J AM Ger Soc 2008:56 (4)593-599
Elsayem et al J Clin Oncol 2004;22 (10) 2008-14
Higginson et al J Pain Symptom Manage 2003; 25(2) 150-168
Ringdal et al Pain Symptom Manage 2002; 24 (1) 53-63
Temel et al N Engl J Med. 2010 Dec 2;363(23):2263

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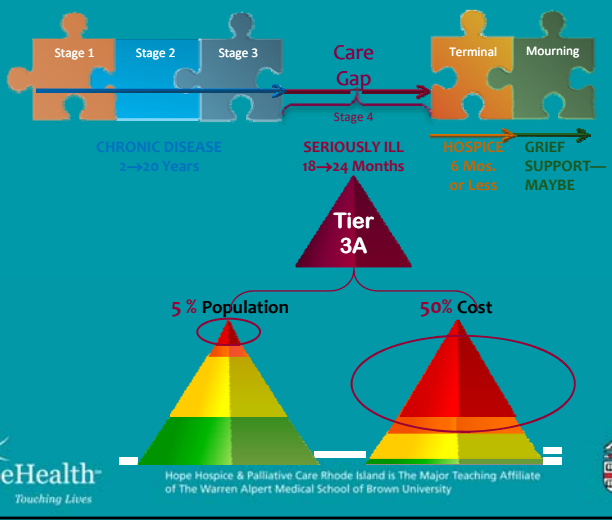
And More Good News



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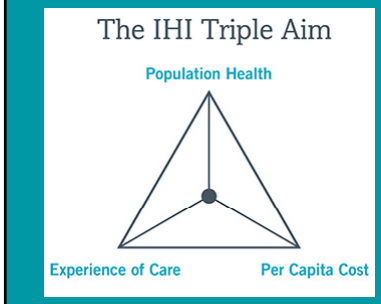
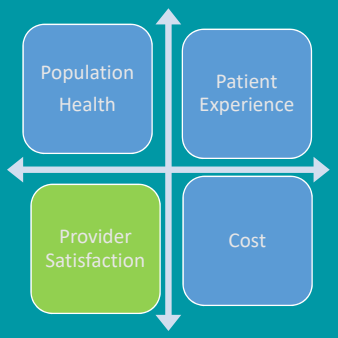


Quadruple Aim



To be of *Value* in health care today

$$\text{Value} = \frac{\textit{quality}}{\textit{Cost}}$$

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Adding "Values"

- **More than highest quality at lowest cost**
- **Not "What is the matter with you?" but "What matters to you?"**
  - **What ability is so precious to you that if it were gone would make your life not worth living?**
  - **If time is short, what should we be focused on?**

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The Bad News…

- Goal is "Palliative Care Everywhere"
- Significant gaps- community, outpatient, rural
- Misaligned incentives
- Currently no such thing as a "palliative care benefit"

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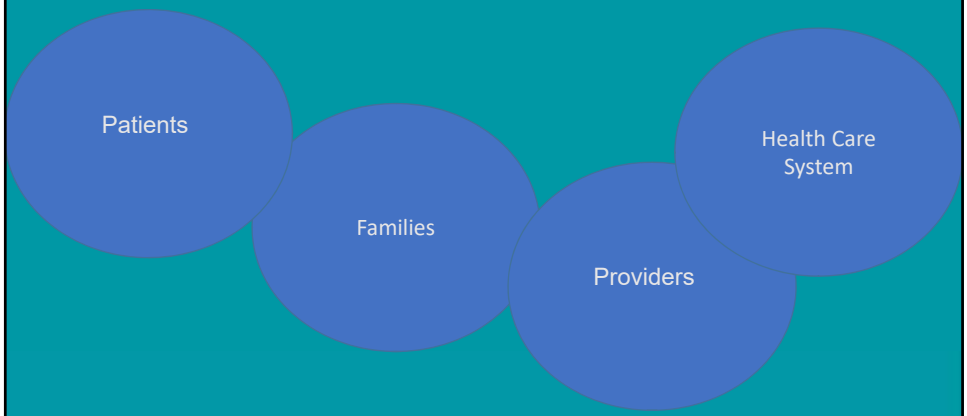
More Bad News…Barriers Abound



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Patient's Preference

Senior Citizens and Assisted Living residents (dementia excluded) asked to rank:

- living longer
- good pain and symptom control
- maintaining independence/not burdening familes

Fried et al. Arch Int Med 2011; 171:1854

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Survey says...

1. 76% Maintain Independence
2. Good pain and symptom management
3. Living longer

This is NOT withholding or rationing care - this is aligning care with preferences…added value

But what does our health care system try to do?

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And…We have an image problem

- 80% adults surveyed do not know what pall care is, but 94% want it when they know
- Physicians say they know but don't
  - Pall Care does not equal hospice or EOL care
- Physicians anxious to recommend it as referral could be misinterpreted
- "Supportive Care, Advanced Illness Care"
- "a rose by any other name would smell as sweet"

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Barriers- too little too late

- "By invitation only"
- Inpatient Pall care reaches patients usually days to weeks before death
- Need to meet palliative patients 18-24 months before death, or sooner
- Must move upstream and into community despite challenges

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Too Little Personnel

- Not enough specialists to serve at risk population- need will increase
- Presently graduating only 300 fellowship trained MDs/year
- Must be a core skill of ALL clinicians who touch patients

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Core Skills for Providers

- Focused on DDx , procedures
- Deemphasized emotional and values
- Experts advise that educating the work force is as important as building out formal programs
- Patients can tell in 40 seconds when a provider is empathetic and judges them as “expert”

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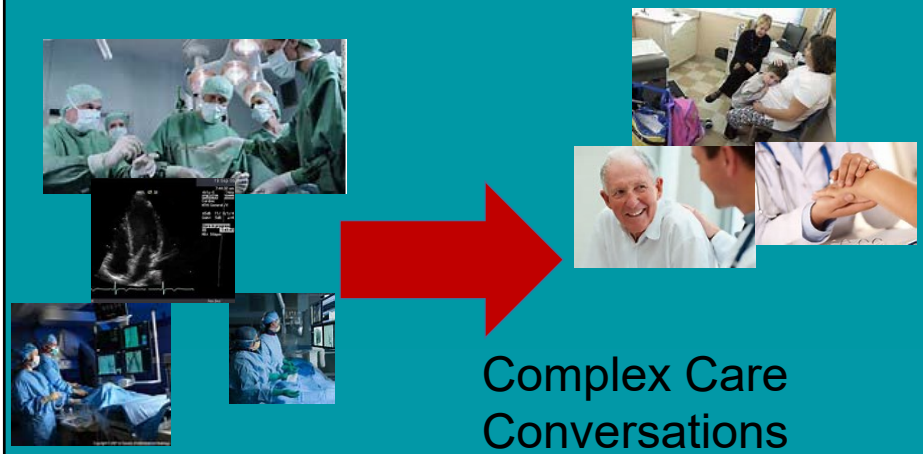
Communication is a Procedure



Complex Care Conversations

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The Southern Jersey Turnpike

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The Northern Jersey Turnpike

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The Role of the Navigator…

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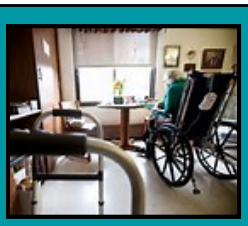


As a result of a failure to prognosticate, let alone prognosticate accurately, patients may die deaths they deplore in locations they despise

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Nicholas Christakis (Emergency Physician Feb 2014, p24-25)

What Would You Want?

- To take a last vacation?
- Spend time with your kids?
- Get your affairs in order?
- Go back to your NH where everyone knows you?

When we wait until the last minute, we rob our patients of this time and irreplaceable memories.

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Do You Want?

- Support
- Dignity
- Privacy
- Help for your family
- Best symptom control possible

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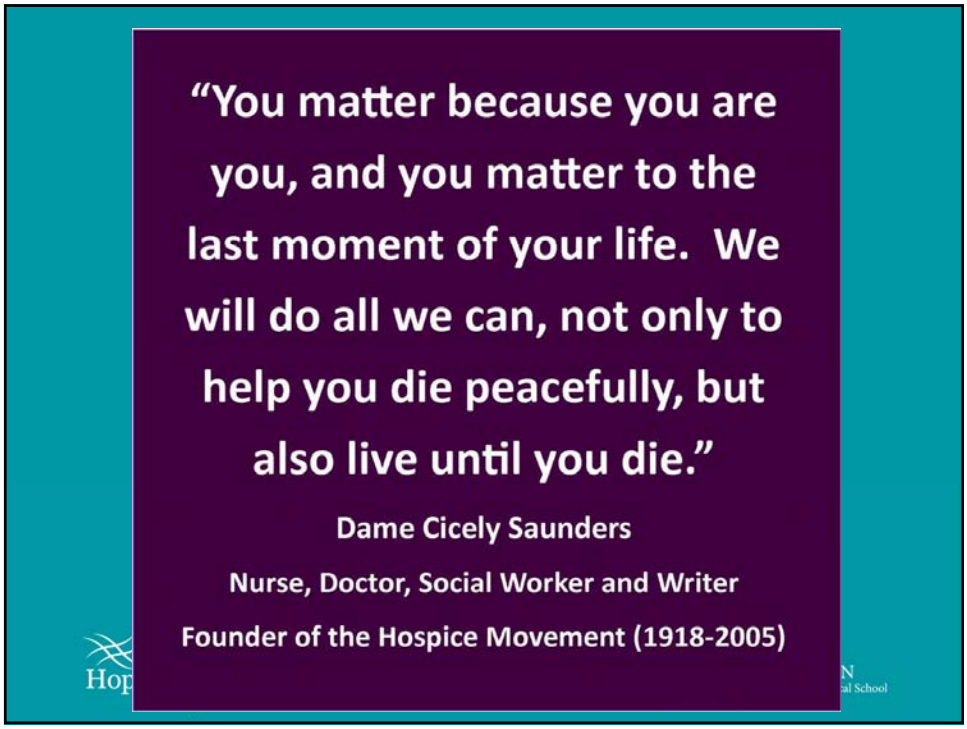

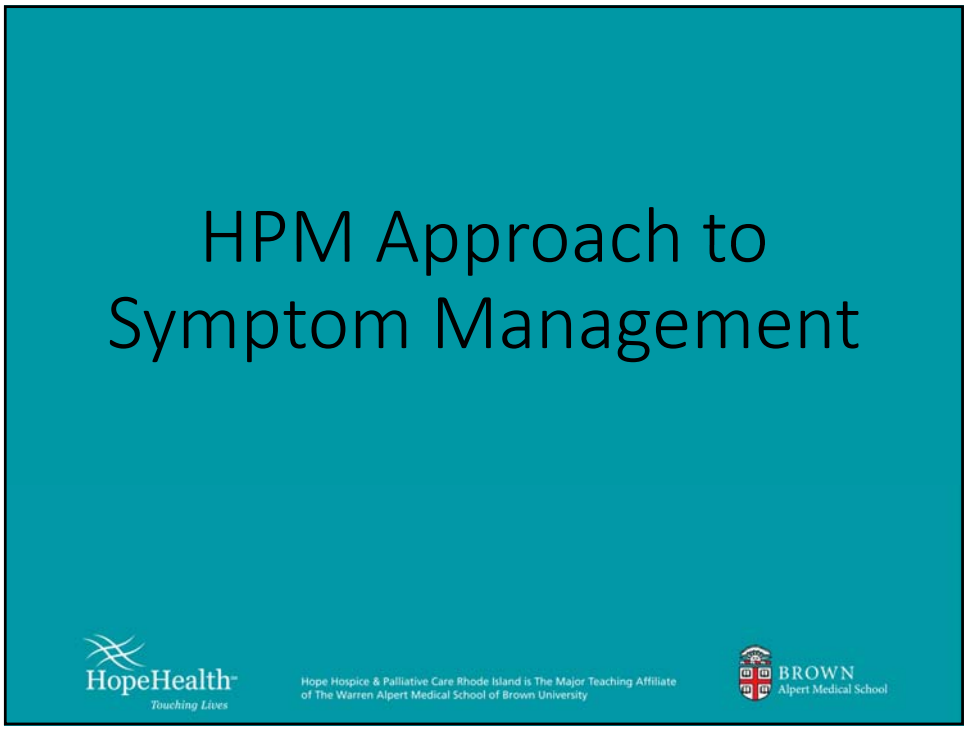

Goal is Comfort and QOL

- Common symptoms with EOL
  - Pain
  - Dyspnea
  - Nausea
  - Fatigue
  - Anxiety

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Manamgent based on prognosis

- Much more willing to aggressively uptitirate when patients are days to week rather than months or years
- Aslo adding meds with long time to work may nmore make sense

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Pain Management

- Generally use opiates as most with maligannt severe pain
- Start with low dose (morphine concentrate 20 mg/ml 2.5 mg q 1 hours prn
- Calculate daily requirements and schedule meds, preferably long acting oral opiates (extended release morphine) with a BT
- BT dose should be 10-15% total daily dose available q 1 hours prn

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Choice of Pain Med

- Again, tolerability and cost are major issues
- Prognosis important
- Use of rectal, sublingual and subq routes
- Sometimes transdermal but challegning in hsopice due to need for rapid titration and a fatty place to place fentanyl patches

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Side Effects

- Pruritus- degranulation of MAST cells
- Fatigue
- Confusion
- Nausea

- CONSTIPATION

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Adjuvants

- Dexamethasone for anti-inflamm effect
- Ketamine to increase opioid sensitivity
- NSAIDs
- Meds for neuropathic pain like gabapentin

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Dyspnea

- Common in seriously ill and terminally ill patients
- Often goes unrecognized even by patients themselves
- Disease directed therapies (eg furosimide, albulterol nebs)
- Non-pharm- cool, moving air (fan)

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Opioids

- Highly effective at low dose to manage this
- Morphine concentrate 20 mg/ml 2.5-5 mg PO or SL q 1 hours prn
- No evidence for respiratory depression at these doses
- Improves V/Q Mismatch
- Can dramatically improve QOL

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Nausea

- Again common and mult etiologies
  - Increased ICP
  - Electrolyte abnormalities
  - SE meds (esp opioids)
  - Bowel Obstruction
  - Fecal Impaction
- First therapy is directed at underlying cause if reversible

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Pharmacologic Therapy

- Dexamethasone great anti-nausea
- Haloperidol 0.5-2 mg q 1 hours as needed
- Lorazepam and scopalaime if vertigious component
- Attention to bowels, venting if frankly obstructed

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Fatigue

- Often mult-factorial
- Meds, disease progression, cachexia

- Again, based on prognosis, trial of antidepressant if appropriate
- As appropriate limiting sedating meds
- Prioritizing activites
- Trial of methlyphenidate

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Anxiety

- Common
- Overlap of Physiologic and Psychologic
- Again looking for triggers

- Antidepressants- SSRI if time to respondf
- Lorazepam 0.5 mg q 1 hours prn

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Delirium

- Often reversible in patients with longer to live (infection, meds, constipation, electrolytes)
- But usually final common pathway as patients approach EOL
- Very distressing to families- cannot say goodbye, not a peaceful death
- Haloperidol can be effective in managing
- Lorazepam if very anxious

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Case Studies

Patient is "Unrealistic"

- 47 yo with ovarian cancer at OLF
  - What mattered to her?
- 39 yo with AIDS, Cardiac arrest and anoxic brain injury
  - what mattered to that family?
- Navigating the balance between medical reality, patient and family values and understanding is THE art of medicine and bread and butter of palliative care

Jenny's Story

Diane Meier, MD
Geriatrician, Pall Care
Founder CAPC

Health Affairs, May 2014