THE RIGHT CARE, IN THE RIGHT PLACE, AT THE RIGHT TIME:
When to Refer to Hospice

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Community Liaison
Heartland Hospice
I work as a Community Liaison for Heartland Hospice, Homecare, IV
OBJECTIVES

1. List 3 statistics that show Delaware has opportunities for improvement in end of life care.

2. Discuss 5 problems which most commonly result in avoidable hospital admissions.

3. Explain how hospice programs address these problems to prevent avoidable hospital admissions.

4. Describe a practical, step-wise strategy for preparing patients/families to consider hospice.
AGING IN PLACE

The RIGHT care
In the RIGHT place
At the RIGHT time
It Takes a Village to Prevent Unnecessary Hospital Admissions

- Coaches/Navigators
- Hospice/Palliative Care
- Pt.-centered Medical Homes
- Home Care (Med. + Non-Med.)
- Long-Term Care
- Outpatient Services
- PACE Programs
Hospitals will likely look to post-acute care networks to assist in managing the care of patients at-risk for re-hospitalization.

Palliative care may be provided under many health plan benefits, including:

- The hospice benefit,
- The home health benefit, and
- Medicare Part B, for physician outpatient or home-based visit coverage.

Tim Cousounis’ Blog: palliativemedicine.blogspot.com
WHAT’S THE DIFFERENCE?

Palliative Care

• Provided by an interdisciplinary team of specialists
• Focused on quality of life by relieving:
  • pain
  • symptoms
  • stress of serious illness
• Provided at any stage of an illness, along with curative treatment

Hospice

Palliative care in the last 6 months of life, after curative treatments stop

Palliative Care is provided “further upstream” from hospice.
HOW DO HOSPICE & PALLIATIVE CARE FIT TOGETHER IN THE CONTINUUM OF CARE?

Curative Care: Treatment of disease aimed at cure

Palliative Care: symptom management, family support, medical decision-making

Hospice Care

Bereavement

Period of living with illness

About 6 mos.

About 13 mos.

Diagnosis

Death
About Our Team

Our professional and experienced team assists you and your family by providing exceptional home care services. We will help arrange for medical supplies and equipment needed to offer the best health care in the comfort and familiarity of your own home.

Our services are just a phone call away, 24 hours a day, seven days a week.

Our Caring Way team includes:

- The patient's physician who can remain in charge of the patient's medical care and continue regular contact with the Caring Way nurse.
- A registered nurse who visit patients at home regularly to make sure they are comfortable and as pain-free as possible.
- A social worker who is available to provide additional support. Our social workers keep a patient's friends and family informed and can offer emotional and psychosocial support.
- A home health aide to assist with personal care, such as feeding, bathing, dressing, and changing bed linens.
- Physical and occupational therapists are available to help patients with maintaining independence and adapt to physical limitations. Therapists can help increase mobility and relieve pain.

Support for the Entire Family

The patient's family and caregivers also benefit from the support of our entire team. We recognize that an advanced illness affects more than the patient. We encourage family involvement by offering education and advice.
HOW DOES HOSPICE PREVENT READMISSIONS?

- Help with Medical Decision-Making (MOLST form)
- 4 levels of care
  - Routine Home Care
  - General Inpatient Care (when symptoms are out of control—in a hospital or IPU)
  - Continuous Care/Crisis Care (1:1 caregiver at home while symptoms unmanaged)
  - Respite Care (5 days in LTC or Hospice IPU for family support)
- SW/Chaplain provide support, teaching, stress-management
- RN Case Mgr.’s and CNA’s educate and manage symptoms, equipment, meds., ADL’s
- 24 hour Nursing + Counseling to manage off-hours issues
- Hospice Medical Director available for orders, home visits
Conversations about readmissions and about palliative care seem to operate in parallel universes that just aren't talking to each other.

Hospice and palliative care advocates need to step forward as major parts of the solution to the problem of readmissions.
“We struggled with caring for my Dad for months. He was in and out of the hospital 3 times in 4 months. We were exhausted, and we really needed help.”

“The doctor kept offering more treatments. I wanted to stop, but I didn’t want to disappoint everyone.”

“We wish we’d started hospice sooner.”
My Mother died last week.

My Mother always had an aggressive personality, and that only became **amplified at the end**.

I cannot imagine what this last 4 or 5 months would have been like without the help of hospice . . . .

I am very proud of her and what she accomplished . . . .

My Mother gave me many wonderful things: love of music, love of inquiry, knowledge of what makes a rich life . . .

It’s easy to forget that they were once young and vibrant and full of hope and optimism for the life ahead . . .

Nurses were always pleasant and smiling.

They helped us through it with compassion, poise, and professionalism . . . .

Reverend Bob cut through my Mother’s angry atheism to give her and us great comfort.
Hospice is a community of people, dedicated to the relief of suffering, who help make possible opportunities for growth at the end of life.”

--Steven R. Connor
HOSPICE IS END-OF-LIFE CARE, NOT BRINK OF DEATH CARE.
WHEN THE TIME COMES . . .

Most people say they want to die at home

But 75% die in a hospital or nursing home

If you want to stay home, you need a plan. Hospice care helps match treatments to preferences.

EMPOWERING PATIENT’S TREATMENT CHOICES—
INFORMED CONSENT = ACCURATE INFORMATION ABOUT PROGNOSIS
AND OPTIONS, INCLUDING PALLIATIVE CARE AND HOSPICE.

Health System Efforts

Legislative Efforts

CA, PA, WV

- Launched initiatives to improve communication about prognosis and treatments options between doctors and patients.

NY

- Passed legislation requiring physicians to discuss palliative options with terminally ill patients.
WHAT IS THE CONVERSATION PROJECT?
Share with your patients/families

Share it with your own family
Joint Commission—New Speak UP Initiative features Palliative Care—
jointcommission.org/speakup.aspx

What you need to know about your serious illness and palliative care was developed in collaboration with

American Academy of Hospice and Palliative Medicine
www.aahpm.org
Association of Professional Chaplains
www.professionalchaplains.org
Center to Advance Palliative Care
www.capc.org
Hospice and Palliative Nurses Association
www.hpna.org
Lance Armstrong Foundation
www.livestrong.org
National Association of Social Workers
www.socialworkers.org
National Hospice and Palliative Care Organization
www.nhpco.org

When you have a serious illness or health problem, you may need palliative care. Palliative care is special health care that can ease pain and other symptoms and side effects from your illness or treatment. It can help you and your family cope with your illness, as well as emotional, practical and spiritual concerns. Palliative care can help you feel better and assist you in dealing with:

- Breathing problems
- Nausea
- Constipation
- Pain
- Depression
- Sleeping problems or fatigue
- Exhaustion
- Spiritual and emotional support
- Loss of appetite

It can also help with:

- Decision making
- Managing your health care
- Planning the future
- Recommending financial resources
- Supporting family members

This brochure will help you and your family talk about palliative care. It will also help you better understand how palliative care can help you.

The Joint Commission is the largest health care accrediting body in the United States that promotes quality and safety.

Helping health care organizations help patients
POLICY PRIORITIES

2. Support for PCHETA
   Interdisciplinary training, education, and support for palliative specialists

3. Preventing Drug Shortages
   Including palliative drugs (not just “life-saving drugs”) on any list of critical drugs

4. Balanced Pain Policy
   Protecting access / Preventing misuse / Focus on education

5. Hospice Regulatory Reform
   Include Hospice Nurses in policy efforts to reform hospice regulations
Why?  
When?  
How?  

To talk about hospice?
"There's no easy way I can tell you this, so I'm sending you to someone who can."
The “H-Word”

“HOSPICE”
Be afraid. Be very afraid.
WHY HAVE DIFFICULT CONVERSATIONS WITH PATIENTS AND FAMILIES?

They’re difficult because we don’t want to hurt our patients.

The goal is to empower patients and help them plan for the future.

From an interview with An Expert Interview With Cyndi Cramer, BA, RN, PCRN
Forced Choice:
Die tomorrow, or die in 1 month? Why?

- Mend fences/relationships
- Financial planning
- Unfinished work
- Bucket list (travel, visit, re-connect)
- Time with loved ones

When we avoid talking about prognosis and options, we deny our patients that time.
WHY? BECAUSE FAMILIES SUFFER WHEN PATIENTS HAVE A “DIFFICULT DEATH”

Many surrogate decision makers experience symptoms for up to 20 years or more after a death

- Avoidance
- Intrusion
- Hyper-arousal
- PTSD!
Patients with cancer who die in a hospital or ICU have worse QoL compared with those who die at home.

Their bereaved caregivers are at risk for developing psychiatric illness.

Interventions aimed at terminal hospitalizations or hospice utilization may enhance patients' QoL at the EOL and minimize bereavement-related distress.

JCO October 10, 2010 vol. 28 no. 29 4457-4464
WHY? BECAUSE LATE HOSPICE REFERRALS LOOK LIKE THIS:

- Woman with ovarian cancer
  - Referred to hospice by her oncologist on a Friday afternoon
  - Our admission nurse arrived at 5:30
  - Pt. died within minutes of her arrival. She was not able to be admitted.

- A 47 year old man
  - End-stage lung cancer
  - referred to hospice during a hospital admission.
  - Admitted directly to the Heartland House.
  - 2 young children were visiting during the admission
  - Pt. died within 2 hours of being admitted.
WHEN SHOULD YOU INTRODUCE HOSPICE?

When is pt. ELIGIBLE?
- 6 mos. or less life-expectancy
- No curative treatments

When is pt. READY?
- Very few people are EVER ready
- Most later say they wish they’d started sooner.
“NOBODY WANTS TO DIE—
AND NOBODY WANTS TO DIE BADLY.”

Judith E. Nelson, M.D.
Director of Intensive Care Unit
at Mount Sinai Hospital, NY
From PBS Frontline
11/23/11
“Facing Death”
WHEN TO REFER TO HOSPICE: ADVICE TO PHYSICIANS

1. **Pt. no longer responds to treatment**
   SOB, chest pain, fluid overload, cancer progression, jaundice, ascites, lack of mobility, etc.

2. **Change in the goals of care**
   “No more tests”, “I just want to go home”, “I’m tired”, “I don’t want surgery”

3. **Acute medical event**
   Cardiac pt. has an MI, dementia pt. gets aspiration pneumonia, parkinsons pt. gets a stage III decub.
When a patient has a progressive, advanced illness

Suggest hospice BEFORE IT’S NEEDED

“At some point, you may get sicker and weaker, and need help at home.

Here’s some information about home care/hospice (brochures)

Familiarize yourself with the services they offer

Let me know when you’re ready.”
"...Hospice is about making sure the patient has the very best day possible, today. . . .

Medicine asks you to give up a good day today in exchange for better health in the future.

For most of our lives, that makes sense. . . until it doesn’t."

--Atul Gawande, MD
Boston Surgeon, MacArthur Fellow, Author; New Yorker Columnist
SHEILA’S CHECKLIST FOR HOSPICE ELIGIBILITY

- Function declines in spite of therapy
- Weight loss in spite of efforts to improve intake
- Worsening symptoms in spite of treatment
- Repeated
  - Hospital admissions
  - Infections
  - Skin break down
  - Falls
- Pt. with cancer stops curative treatments
- When patient has serious signs/symptoms but refuses or is not appropriate for work-up/treatment
Q: HOW DO YOU INTRODUCE HOSPICE?
A: Very carefully!
S.P.I.K.E.S.—A SIX-STEP PROTOCOL FOR DELIVERING BAD NEWS

**Setting**—Privacy, include significant others, sit down, manage time, make a connection

**Perception**—(ASK-TELL-ASK) “What do you understand about your medical situation so far?” “What did you think was going on with you when you felt the lump?” “What have you been told about all this so far?” “Are you worried that this might be something serious?”

**Invitation**—Ask the patient if they would like to know more about their illness, their prognosis, their treatment options. (ASK-TELL-ASK):

**Knowledge**—Share the bad news. Give a warning shot “I’m sorry to say I have some bad news.” “Unfortunately, the treatment is not working.” “I wish things were different, but . . .” Avoid excessive bluntness. Avoid jargon. Don’t say “There’s nothing more we can do”. Never say “Withdrawing care”. Patients feel abandoned when they hear this. We can always provide care—we adjust our plan of care when prognosis and goals change.

**Empathy**—Respond to the patient’s emotion—anger, denial, sadness, relief, etc. (“I can see this is upsetting for you”. “I was also hoping for better results”, “I can tell you weren’t expecting to hear this.” “I will continue to care for you no matter what happens.”) If emotions are not expressed, ask more questions.

**Strategy**—Present treatment options, including palliative care, if appropriate. Work with the patient to come up with a plan, and schedule follow up.
HOW CAN YOU INTRODUCE HOSPICE?

- What do you hope for most in the next few months? What else?
- Is there anything you are afraid of?
- It can be very difficult to care for a family member at home. Have you thought about what kinds of help you might need?
- Would it help if we could find a way to deliver your medications to you?
- Would it reassure you if we could send a nurse out to check on you at home?
- One of the best ways to get the help you’ll need to stay at home is hospice. Have you heard of hospice?
- Hospice helps people live as well as they can for as long as they can.
- Hospice teams have a lot of experience taking care of people with serious illness at home.
- Hospice is able to provide more support and services than most other home care services.

Casarett D J, Quill T E Ann Intern Med 2007;146:443-449
POOR COMMUNICATION

- Hurried
- Healthcare provider is doing all of the talking
- Using medical jargon the patient doesn't understand
- Being distant
- Not engaged

GOOD COMMUNICATION

- Not rushed
- Simple words
- Mostly listening
- Giving small bits at a time
- Following cues
- Being empathetic
- Being "present"
SIGNS OF THE WRONG CARE, AT THE WRONG TIME, IN THE WRONG PLACE:
(QUALITY INDICATORS FOUND IN RECENT STUDIES)

- In the last week of life
  - Dialysis
  - Chemotherapy
  - Feeding tube placement
  - ICU admission
  - No offer of hospice/palliative care (WVAMC—all dying pts. get p.c. consult)
- Pt. w/ terminal illness and no advance care plan in place

- In the last 2 days of life
  - Transfer to a new care setting

These signs should prompt us to look for ways to do better.
DO WE IN DELAWARE DO A GOOD JOB CARING FOR PATIENTS WITH ADVANCED ILLNESS?
A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals

DELaware

Grade: F

Select a County for a List of Palliative Care Programs

STATE RANKINGS

Click on a hospital group to compare the state, regional and national values in a chart.

For a full provider directory, visit getpalliativecare.org.
IT’S NOT AS BAD AS IT LOOKS--

- V.A. and Pediatric Hospitals were not counted (M’care and IHI data were used.)

- St. Francis Hospital’s palliative care service missed deadline for inclusion.

- Data did not account for hospital size: (CCHS counted equal to Beebe)
<table>
<thead>
<tr>
<th>Region</th>
<th>Medicare Reimbursements per Decedent, by Interval Before Death, Sector, and Program Component (Interval Before Death: Last Two Years of Life; Sector: Hospice; Program Component: Overall; Year: 2003–2007; Region Levels: State)</th>
<th>Percent of Decedents Enrolled In Hospice during the Last Six Months of Life (Year: 2003–2007; Region Levels: State)</th>
<th>Hospice Days per Decedent during the Last Six Months of Life (Year: 2003–2007; Region Levels: State)</th>
<th>Inpatient Days per Decedent During the Last Six Months of Life, by Gender and Level of Care Intensity (Gender: Overall; Level of Care Intensity: Overall; Year: 2007; Region Levels: State)</th>
<th>Percent of Decedents Admitted to ICU/CCU During the Hospitalization in Which Death Occurred, by Gender (Gender: Overall; Year: 2007; Region Levels: State)</th>
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</thead>
<tbody>
<tr>
<td>Delaware</td>
<td>$3,723</td>
<td>42.4%</td>
<td>18.8</td>
<td>10.9</td>
<td>17.2%</td>
</tr>
<tr>
<td>National Average</td>
<td>$3,212</td>
<td>36.7%</td>
<td>15.3</td>
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<td>90th Percentile</td>
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<td>13.8</td>
<td>9.7</td>
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</tr>
<tr>
<td>10th Percentile</td>
<td>$1,788</td>
<td>23.5%</td>
<td>8.6</td>
<td>6.9</td>
<td>11.4%</td>
</tr>
</tbody>
</table>
HOW MANY PALLIATIVE CARE CERTIFIED PROVIDERS DOES DELAWARE HAVE?

- ABHPM’s = 8
- ACHPN’s = 4
- CHPN’s = 65
- CHPLN’s = 10
- CHPNA’s = 44
- CHPCA’s = 3
DELAWARE NOW HAS A NEW EMS REGULATION IN PLACE

EMS Providers will honor a new form called Medical Orders for Life Sustaining Treatment (or MOLST) to take the place of the PACD.

*State of DE has stopped printing the PACD
OUR DE MOLST

Should be printed on purple cardstock and looks like this:
MAKE IT EASY FOR EMS PROVIDERS TO FIND THE MOLST

- In a facility, file it in the front of the medical chart.
- In a home, display it on the refrigerator, the bedroom door, or above the bed.
POLST/MOLST Works to match treatments to preferences

11/11 Study* showed 94% overall consistency rate between POLST orders and treatments given.

*Study included 90 nursing facilities in OR, WI, WV.
WE NEED TO PROVIDE BETTER CARE FOR PEOPLE WITH ADVANCED ILLNESS

Hospice and Palliative Care can be a part of making that happen.

Hospice/ Palliative Care
Pt.-centered Medical Homes
Long-Term Care
Outpatient Services
Coaches/ Navigators
Home Care (Med. + Non-Med.)
PACE Programs