Life Choices
A Program of Palliative Care

Relieves suffering and improves quality of life for patients with advanced illnesses

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What is Palliative Care?

Medical treatment that aims to relieve suffering and improve quality of life simultaneously with all other appropriate treatment for patients with advanced illness, and their families.

Palliative?

From the Latin word *pallium* - means to cloak or cover, or to moderate the intensity of... (a disease).

Palliative can refer to any action, or any medical intervention that reduces suffering.

Hospice care is palliative care.

Palliative care emerged

- Dr. Balfour Mount of Royal Victoria Hospital in Montreal coined the name of the first "palliative care program" to distinguish it from hospice
- Needed by patients before the “six months” allowed by Medicare
- Needed by those actively seeking cure
**Palliative Care Model**

- **Disease Modifying Therapy**
  - Curative or restorative intent
- **Palliative Care**
- **Life Closure**
- **Death & Bereavement**
- **Diagnosis**

**Key Differences**

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<th>Palliative Care</th>
<th>Hospice</th>
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<td>- Program open to all seriously ill patients</td>
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<td>- Patients do not have to forego curative care if this is covered by their insurance.</td>
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<td>- Palliative care team works with a variety of health care providers including specialist and primary care physicians to prevent service fragmentation</td>
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<td>- New, evolving, resulting in differences in palliative programs</td>
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<td>- Six month prognosis required by Medicare and other payors.</td>
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<td>- Coverage includes outpatient medications and supplies but efforts to cure or prolong life are not covered</td>
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<td>- Hospice Team coordinates and oversees the plan of care</td>
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<td>- The Medicare Benefit Conditions of Participation provides some consistency in program contents</td>
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**Service Provided**

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<td>- Care of psychological and spiritual needs, family support</td>
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**Patients Served**

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<td>Patients of any age, at any stage of advanced and life-threatening illness</td>
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<tr>
<td>Dying patients of any age</td>
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Do we need a new program?

What Hospice Touch experienced:
- In 2005 to 2006 the average length of stay for Hospice Touch patients was 59 days.
- 29% of these patients died within 7 days of admission and 13% died within 3 days of admit.
- Results in providing crisis intervention to patients and families but not quality end-of-life care.

The Demographic Imperative
The Reality of the Last Years of Life:
Death is not Predictable
(slide courtesy of Joanne Lynn, MD Rand Corp.)

Advances in Medicine
- More can be done with life-extending treatments
- Sometimes “more” is not better
- Patients choice? Or lack of communication
- Assess the patient’s goals of care
- Honest communication
The demographic imperative: Chronically ill, aging population is growing

- The 63% of Medicare patients with 2 or more chronic conditions account for 95% of Medicare spending (CDC)
- The number of people over age 85 will double to 9 million by the year 2030 (CDC)

Health Care Costs

Demand for palliative care: What patients want from the healthcare system

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

What Do Family Caregivers Want?

Study of 475 family members 1-2 years after bereavement
- Loved one’s wishes honored
- Inclusion in decision processes
- Support/assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to
- Privacy
- To be remembered and contacted after the death

Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics

The Abiding Desire Not to Be Dead

I don’t want to achieve immortality through my work. I’d rather achieve it by not dying.

Woody Allen

Studies of patients with serious illness report increasing desire for aggressive therapies as health status declines.


THE WALL STREET JOURNAL

Final Days
Unlikely Way to Cut Hospital Costs: Comfort the Dying

Palliative-Care Unit Offers Painkillers and Support, Fewer Tests, Treatments

“There's no easy way I can tell you this, so I'm sending you to someone who can.”
How to Communicate

- Establish realistic, attainable goals of care
- Help patients and families understand scope of illness and likely progression
- Identify relevant values and goals
- Define “acceptable” and “unacceptable” quality of life
- Define choices to be made and their benefits and burdens
- Help with decision-making
- Develop care plans that maximize chances that goals will be achieved

The Epiphany

- Progressive hospices have accepted the challenge of leveraging what we know how to do: interdisciplinary palliative care services (or whatever term you prefer) for a patient population whose needs/preferences extend beyond the boundaries imposed by the Medicare Hospice Benefit.

Life Choices Palliative Care Team

Life Choices patients may have one or more of the following issues:

- A persistent or recurring condition that adversely affects their daily functioning or will predictably reduce life expectancy
- Multiple health problems
- Frequent readmissions to hospital
- A need for more help or services
- A need for emotional support
- Are at a point where discussions of options and goals may be beneficial
Life Choice Services

What type of Service?
- Consultation Service (Advanced Practice RN consult made at Physician request, to assist with discussion of options and recommendations of care)
- Primary Service (patient admitted to palliative care program, access to 24/7 RN on-call, Advanced Practice RN/Clinical SW visit in home or office)
- Referral to Physician, Chaplain, Social Worker and any area and community resources
- Offer community patient and caregiver support groups

It’s a Journey

Premise
- 12-2007 $40,000 grant to start program cooperatively with Mile Bluff Medical Center in Mauston.
- 3-2008 Hired Part-time NP and ads out for Clinical SW.

Learned
- Need to start somewhere and get it right before you expand.
- Part Time NP doesn’t stretch far; neither does $40,000.
- Clinical SW is not what we needed.

Hang on; it can be a wild ride

Premise
- 6-2008 Tomah Memorial hospital would do the billing for NP visits; private pay RN, SW, NA, Chaplain.
- Use the same forms as hospice, modified.

Learned
- Credentialing is a lengthy process. (3mos)
- Billing is complicated, very frequent meetings with billers to get it incorporated into hospital system.
- People do not want to pay for SW or Chaplain visits.
- No one, including insurance programs, knows what palliative care really is.
- Need for tools to explain and solicit referrals.
More lessons learned

Premise
- Palliative care should incorporate well with the current hospice team, i.e., hospice is palliative care.

Learned
- Very complicated patients; heavy-duty symptom management.
- Much wider focus and goals of care
- 12-2008 Another SW hired.
- 3-2009 RN Palliative Care Coordinator position.
- 9-2009 Full time NP hired.

YES!
- No more "NO"
- If patient’s don’t meet hospice criteria, you have something to offer them—palliative care—expert pain and symptom management.
- If patient is having curative treatment, yes we can help you!
- If the patient improves and must be signed off hospice they are continued to be helped with palliative care.
- Improved patient, family, and staff satisfaction.

The current process is:
- Referral from physician, family, patient
- Order for pc from physician with symptom to be palliated
- Insurance check done
- Telephone contact with patient; appt. for consult
- Consult done by Nurse Practitioner
- If appropriate for palliative care program, NP asks if interested in Life Choices program
- SW makes appt. to explains program, gets information for sliding fee scale, and papers are signed if patient desires services.

Services provided are:
- SW does complete assessment and helps identify patient needs and goals of care and community resources and interventions.
- SW does follow-up visits until needs are stabilized.
- Then calls monthly; visits as needed.
- Volunteer is offered if needed; also chaplain, and nursing assistant.
- NP visits every one to two months; more frequent based on need.
- Patient/family call if they have problems or questions.
- After hours hospice on-call staff field calls.
- Team patients minimally every two weeks after hospice Team; and as needed.
Why palliative care?

- You don’t have to say “NO”
- It’s a good thing! The right thing to do.
- Patient autonomy and choice and goals honored.
- Futile care and unnecessary suffering prevented.
- Patient/family/physician/hospital satisfaction with symptom management and improved quality of care and life
- You can say “Yes” we can help you!

Challenges:

- Palliative care is not a Medicare Benefit and rarely recognized by insurances.
- Need for highly skilled practitioners; patients are complex.
- Palliative care state surveys will be done with hospice, home care, nursing home surveys.
- JCAHO will soon have a PC survey.
- These patients may be on program for years.
- Few comparative programs for community palliative care.
- Comparative data hard to find.

Although the world is full of suffering, it is also full of the overcoming of it.

Helen Keller
Optimism 1903