Palliative Care vs. Hospice Care

What’s the Difference?

Presenters

- Carlos Monguilod, MD Chief Medical Director, HPCG
- Marcia Vanard, LCSW, Director of the Counseling and Education Center, HPCG

Lunch and Learn at the Lusk Center
Thursday, March 15, 2018
The Story of Hospice

Cicely Saunders is the founder of the modern Hospice movement. A hospital nurse in post-war England during the 1940’s, she cared for, and became very close to, one of her patients -- David Tasma. Although this relationship only lasted a few short months until David’s death, it planted the seed for the modern hospice movement.

David had come to England as a Jewish refugee from Warsaw, Poland a few years earlier, and now he found himself dying of cancer at age 40. David’s cancer caused him to suffer from relentless pain -- for which the medicine did little to alleviate. Cicely was distressed by the fact that he and others had to die in physical pain, and she started to wonder if maybe she could devote her career to finding more effective medication regimens for such pain.

But David’s unmanaged physical pain was clearly only one aspect of his suffering. He was also suffering emotionally and socially. With no family in England, and with only a few friends, he was deeply lonely. He was saddened that he would die in this foreign culture, away from all that was familiar. His pain was spiritual as well. He wondered if his life had meaning, if he had fulfilled his purpose. He had regrets. He feared his impending death.

Through her efforts to bring David comfort, Cicely grew more aware of the needs of the dying. She and David agreed that much more could be done to ease their suffering. Through their long conversations, she developed the idea of creating a special, welcoming place for dying people, where they would be treated with the skill and caring that they deserved. David bequeathed to her what little money he had (500 pounds), stating, “I’ll be a window in your home.” He died shortly thereafter.

Cicely spent the next two decades preparing to turn this idea into a reality. She returned to school to become a doctor. She raised money. As she cared for patients she listened to their unique stories, and their unique needs. She developed a profound respect for every individual’s right to come to the end of their life’s journey in their own way.
The Heart of Hospice

The heart of hospice is understood in this often-quoted statement by Cicely Saunders:

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also, to live until you die.”

Cicely, along with others of her era (like Elizabeth Kubler Ross) challenged our ‘death-denying culture.’ She asserted that “dying is as natural as being born.” Like birth, it should be a life-affirming process and as free of pain as possible.

She also challenged the doctors who saw patients with terminal illness as medical ‘failures’. She challenged doctors to see that their role did not end when a cure was no longer possible. She refused to accept the doctor’s refrain, “there’s nothing more we can do.” Instead, she argued, there is much to be done when a patient is at end of life.

In creating hospice, Cicely sought to treat what she called “total pain” – the physical, emotional, social, and spiritual distress that she had witnessed in David Tasma and many others. Cicely developed a more effective system for medical management of pain. But she also ensured that her new hospice offered compassion, respect, listening, spiritual support, companionship, and support of family.

“Suffering is only intolerable when nobody cares. I once asked a man who knew he was dying what he needed most from those who were caring for him. He said, ‘For someone to look as if they are trying to understand me.’”

When St. Christopher’s Hospice opened its doors in 1967, David’s window was at the entrance. His contribution was marked by this plaque.
The Hospice Program...how it works

Where is Hospice?
Hospice provides services wherever the patient calls home: a private residence, a nursing home, assisted living facility, or a hospice home (like Beacon Place). Hospice also serves patients in the hospital.

What makes a person eligible for hospice?
A terminal illness, and a life expectancy of six months or less.
There is no cure -- or the patient is choosing comfort care instead of curative care.
Two physicians will certify that the patient is appropriate for hospice care.

How do you know when it’s time for Hospice?
Look for decreased ability to carry out usual activities. Also consider weight loss, frequent infections, increase in hospitalizations, more pain, more weakness. Discuss it with your doctor. Sometimes doctors don’t feel comfortable raising the issue themselves.

How does a family or person get Hospice care started?
Somebody – the patient, a family member or friend, or the doctor -- starts the process by calling hospice. Hospice communicates with the doctor, patient, and family.

When patient is deemed eligible, Hospice arranges with patient to make an ‘admission visit.’ Once patient or family members sign consents for hospice services, the patient is officially under Hospice care.

What does Hospice provide?
A circle of care.... a team of professionals who offer their expertise and compassion in the service of a dying persons’ comfort and in support of their loved ones and caregivers.

A plan of care that is created by hospice team, patient and family – it sets forth the patient’s goals, and action steps to try to meet those goals.

In most cases, Hospice provides medication related to patient’s comfort care. Hospice provides medical equipment – hospital bed, walker, wheelchair, shower chair, bedside commode, oxygen tanks or concentrator. Some supplies are also provided.

Hospice provides 24 hour/7 day a week support. There is always someone to call if a patient or family needs consultation or support. The nurse can make a visit as needed.

Volunteers can be companions, run errands, or provide respite to the caregiver. Under standard Medicare or Medicaid, there is a longer respite option. A patient can stay at a
nursing home or hospice facility for up to six days so that family or caregiver can get much-needed rest or go out of town.

When a patient dies, a hospice nurse can come to the home or facility to call the death, report to the patient’s doctor, and offer support to the family.

After a patient’s death, hospice continues to offer grief support to those left behind.

**What does Hospice not provide?**

Except at Beacon Place, Hospice staff do not stay with the patient – they only visit. The actual care is provided by family, friends, hired caregivers, or facility staff.

**Who pays for Hospice?**

Medicare Part A and Medicaid provide hospice with a daily rate – this is used to cover all expenses for the patient – visits from nurse, hospice aide, chaplain, social worker, medication, oxygen, hospital bed, walker, etc.

Some private insurances pay for hospice care – hospice can help a patient determine what is covered under their plan.

**What costs might a patient or family be responsible for?**

If there are items or services not covered by their insurance, Hospice will inform them of these expenses.

Treatments, services, or supplies that are not in the patient’s plan of care. Medications not related to the terminal illness.

If a patient goes to Beacon Place, there may be charges for room and board for some of the days that they stay there.

If a person has no insurance, they may still receive hospice care. HPCG will provide this care and the patient/family will pay what they can afford.

**How does Hospice help family and friends?**

By offering support and education. By helping them anticipate the needs of their loved one and how these needs might best be met. By being a calm voice at the other end of the phone during tough moments. By helping them think through hard decisions. By listening and caring. By being there for them even after their loved one is gone.

**What do patients and families appreciate most about Hospice?**

- Information shared about the disease and symptom management
- Education about “what to expect” and how to provide care at end of life
- 24/7 availability
- Emotional support for patient and family
“To live well until you die”

Approaching end of a life is not exclusively a sad time. It is also potentially a very rich time – to connect with loved ones, to take stock of one’s life – the good times, the victories, the challenges, the disappointments. The lives we impacted and the people and things that impacted us. What and who have given meaning to our lives.

Hospice care can enhance the richness of this period. For many Hospice care means time and energy for simple pleasures: more family time, more quiet conversations, reminiscing, appreciating nature or a favorite meal.

Sometimes hospice also helps create opportunity for new friends, new experiences, or one final adventure.
Are all Hospices the same?

No. Hospices are not all the same. At present there are more than a dozen hospices operating in Guilford County.

HPCG is proud of its almost 40 years of nonprofit service to Guilford County. With strong community support, HPCG has sought to build programs that meet or exceed the needs of those facing end of life.

All hospices provide care in the home...but few hospices offer specialized end of life care in a beautiful and peaceful setting like Beacon Place.

All hospices provide grief support programming for bereaved family members...but the Counseling and Education Center offers an exceptional depth and quality of care - individual counseling, loss-specific support groups, workshops, memorial gatherings, and expressive arts workshops - provided by skilled, compassionate counselors.

HPCG created the Kids Path program to offer the special care needed by terminally ill children and their families. Kids Path also provides counseling services to grieving children throughout the area.
What is Palliative Care?

Simply put, palliative care is comfort care. Its goals are to provide pain and symptom management and to optimize quality of life.

Hospice is one kind of palliative care program – for those who are near end of life and for those who no longer receive curative treatments.

Other palliative care programs offer options to those who are either not eligible for hospice care or who have not chosen hospice. These programs can vary greatly.

Here is a description of the Palliative Care program offered through HPCG.

HPCG’s Palliative Care Program offers patients and families specialized consultation that focuses on improving quality of life by:

- Helping align patient’s goals with their treatment plans
- Assisting with completion of advance directives
- Helping navigate complex medical decisions
- Relieving symptoms associated with their serious illness

This program is available to patients with a chronic disease at any stage. It can be provided regardless of the patient’s life expectancy and regardless of whether they are receiving curative treatment.

HPCG’s Palliative Care Program services are provided by doctors, nurse practitioners, and a social worker. They then work to communicate and collaborate with a patient’s primary doctor.

Patients and families who receive HPCG’s Palliative Care consultation services have overall had fewer hospital readmissions and Emergency Room visits, and they report higher satisfaction with their care choices and the care they received.

To receive a palliative care consultation, a patient’s doctor or medical provider must make the request.
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“We need to teach the next generation of children from day one that they are responsible for their lives.

Mankind’s greatest gift, also its greatest curse, is that we have free choice.

We can make our choices built from love or from fear.”

~ Dr. Elisabeth Kübler-Ross
The Hospice Story
Dying is not simply a medical event

It is a process, an experience, that is

Physical         Social
Mental           Emotional
Spiritual        Existential

It deserves our attention and compassion.
Hospice was designed...

• To help create a ‘holding space’ for dying persons and their loved ones

• To provide a philosophy of care and tools to help us lean in, move toward, our loved ones, and see them through their final journey.

• To continue to support those loved ones after the death.
Desired Outcomes for Every Patient

- Self-determined life closure*
- Safe and comfortable dying
- Effective grieving for survivors

*Hospice does not speed up nor prolong death
David’s window

at St. Christopher’s Hospice in England
Challenging a death-denying culture

• Hospice changes the medical mindset of:
  “There’s nothing more we can do” to
  “There is much to be done”

• Dying is as natural as being born...
  It should be a life-affirming process.
What Does Hospice Offer?

- **A circle of care**... offering expertise and compassion in the service of dying persons' comfort and in support of their loved ones.

- **A plan of care** that is created by patient, family, doctor and hospice— it sets forth the patient’s goals, and action steps to try to meet those goals.
What else is provided?

- Medical Equipment and Supplies
- Related Medications
- 24 Hour On-Call
- Bereavement Care
- Physical therapy, nutritionist, etc.
- Horticultural therapist, music, etc.
- Respite care (under Medicare/Medicaid)
Who Pays for Hospice?

• Almost 98% of the time, hospice is provided under Medicare Part A or Medicaid. Private insurances often provide a hospice benefit as well.

• Medicare/Medicaid give a daily amount to a hospice (per diem) that is intended to pay for services, supplies, medications, etc.
Where Is Hospice?

Wherever the patient calls home:

- Private Residence
- Skilled-Nursing Facility
- Assisted-Living
- Beacon Place
What makes a person eligible for Hospice?

- A terminal illness, and a life expectancy of six months or less

- There is no cure – or patient is choosing comfort care over curative care

- Physician certifies that a patient is eligible for hospice care
What are signs that it might be time for hospice care?

• Raise the question with your doctor.
• Look for:
  • decreased energy
  • less capacity to do daily activities
  • weight loss
  • frequent infections
  • more hospitalizations
  • more pain
How does Hospice care get started?

- Somebody makes a call to Hospice... that can be the medical provider, patient, family member or friend.

- Hospice completes the communication with all parties and deems eligibility.

- Admission visit is set up. Patient or family signs consents for care....then it’s official.
"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

— Dame Cicely Saunders
Living well until you die

Hospice
and Palliative Care of Greensboro
Living well until you die

It’s not too late to make a new friend
It’s not too late to have one more adventure
“To me, hospice represents quality time, not end of time.”
—Pastor Keith T. Kilgo
What Our Patients and Families Say

Wished that MD had referred to Hospice sooner.

Appreciation for:

• Hospice team’s knowledge of disease and symptom management

• Emotional support to patient and family

• 24/7 support

• Education about “what to expect” and how to provide care at end of life.
Are all hospices the same? Are they all connected?

No, they are not all the same. No, they do not operate under one organization.

Currently there are more than a dozen hospices operating in Guilford County.

HPCG is proud of its history of nearly 40 years of nonprofit service to the patients and families in this area – and of its unique programs that go above and beyond.
View from a Beacon Place Room
Counseling and Education Center

Grief support for Hospice bereaved

Grief support to anyone in the community grieving the loss of a loved one

Assistance with Advance Care Planning
Above and Beyond

- individual grief counseling
- support groups
- workshops
- literature
- memorials

Hospice and Palliative Care of Greensboro
Kids Path Garden
Palliative Care
A program of
Hospice and Palliative Care of Greensboro
Palliative Care Consults

https://www.uchealth.org/today/2016/08/17
Palliative Care

• Palliative care can be for **anyone** with a chronic illness at **any time** during the course of their illness.

• Palliative care is **a consultation service**. As a medical specialty, it does not replace any other medical services the patient is already receiving. The provider communicates recommendations to the provider that manages the patient's care.
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| Who provides these services?                                           | Doctor, nurse practitioner, clinical navigator, and social worker                                                                                                                                      | Doctor, nurse, social worker, chaplain, volunteer, aide, others.                                                                                                                                            |
Considerations as you help a patient develop Goals of Care

• What is possible?

• What are the risks and benefits of treatment?

• What does the patient want??
Palliative Care can help Providers and Patients to:

- Avoid readmissions
- Follow through with goals set in the hospital
- Educate about changes
- Educate about hospice
- Manage symptoms
- Support patient/family
- Encourage communication

Hospice and Palliative Care of Greensboro
How to get Palliative Care?

- To receive HPCG Palliative Care services a patient’s doctor or medical provider must make the referral.
On the “Road of Life”

When to consider palliative or hospice care

Healthy Adult ——— Illness ——— Terminal Illness ——— Death

Preventative Care
Curative Care
Palliative Care
Hospice Care