The “When’s” and “Why’s” of Hospice Care

Prepared by The Weinstein Hospice
What is Hospice Care?

• Hospice care is a philosophy of care that focuses on patient comfort and quality of life rather than curing the patient's disease.

• It is generally appropriate for someone with a terminal illness and a life expectancy of six months or less.
What is Hospice Care?

- There are different levels of hospice care: routine care, in-patient acute, respite care and continuous care.
- Patients are initially certified for 90 days and then must be recertified for a second 90 day period regardless of the level of hospice care they receive.
What is Hospice Care?

- After that, the patient must be recertified every 60 days until he/she dies or is discharged from hospice care.
- During any certification period, patients are entitled to 5 days of respite care in an in-patient setting.
What are the Levels of Hospice Care?
The Levels of Hospice Care

- As part of **routine care**, a patient is visited by an RN two to three times a week. However, an RN (and a hospice physician) is available 24/7 to handle any medical issues.

- A social worker will visit the patient regularly, perhaps as often as once a week, but usually not less often than every other week.

- A nurse’s aide will assist up to three times a week with activities of daily living such as bathing, dressing and feeding the patient.

- A chaplain will visit the patient on an as-needed basis, but only upon the request of the patient or his/her family.
The Levels of Hospice Care

• Acute in-patient care is used when a medical crisis occurs. For a hospice patient, dying is not an acute medical crisis. It is simply part of the hospice process.

• A medical crisis for a hospice patient is one which involves intractable or uncontrollable pain or other symptoms (such as breathing difficulties or hemorrhaging).
The Levels of Hospice Care

• **Respite care** is a standard entitlement which allows the patient to go to an in-patient facility for a 5 day period in order to give respite to his/her family and caregivers.

• The patient is entitled to this benefit every certification period whether or not the patient chooses to avail him- or herself of it.
The Levels of Hospice Care

• Continuous care (which can be provided in the patient’s home or in an in-patient facility) is only provided when Medicare or the patient’s insurance company considers the patient to be in an acute medical crisis.
The Levels of Hospice Care

• Regardless of the level of care a patient receives, hospice providers do not routinely offer 24 hour, round the clock care.
• Many patients are thus either cared for by family members, hired caregivers or nursing home staff.
• Hospice volunteers can help the caregivers with daily tasks such as shopping or sitting with the patient.
Why Hospice Care?
Why Hospice Care?

- The goal of hospice care is to alleviate symptoms and improve quality of life for patients with a life expectancy of six months or less and in situations in which curative treatments are no longer an option.
Why Hospice Care?

• The mission of hospice is to affirm life and view death as a natural process.

• Hospice is not designed to hasten death or “help” someone die, but rather to help patients live the remainder of their lives as fully as possible.

• There is not only dignity in life, but also dignity in dying.
Why Hospice Care?

• Most people, if asked, would choose a peaceful, comfortable death surrounded by their loved ones. An interdisciplinary team of trained professionals work together to deliver hospice services that can make that choice a reality.
How and When to Broach the Issue of Hospice Care?
How and When?

• Consider this scenario. A few days before Thanksgiving, Sara had another CT scan, which showed that the chemotherapy – her third drug regimen – was not working. The lung cancer had spread from the left chest to the right, to the liver, to the lining of her abdomen and to her spine. Time was running out.
How and When?

• This is the moment in Sara’s story that poses a fundamental question for everyone living in the era of modern medicine: What do we want Sara and her doctors to do now?

• Or, to put it another way, if you were the one who had metastatic cancer – or, for that matter, a similarly advanced case of emphysema or congestive heart failure – what would you want your doctors to do?
How and When?

• The issue has become pressing in recent years for reasons of expense. The soaring cost of health care is the greatest threat to the country’s long-term solvency, and the terminally ill account for a lot of it.

• Twenty-five per cent of all Medicare spending is for the five per cent of patients who are in their final year of life, and most of that money goes for care in their last couple of months which is of little apparent benefit.
How and When?

- Spending on a disease like cancer tends to follow a particular pattern. There are high initial costs as the cancer is treated, and then, if all goes well, these costs taper off.
How and When?

• Medical spending for a breast-cancer survivor, for instance, averaged an estimated $54,000 in 2003, the vast majority of it for the initial diagnostic testing, surgery and, where necessary, radiation and chemotherapy.

• For a patient with a fatal version of the disease, though, the cost curve is U-shaped, rising again toward the end – to an average of $63,000 during the last six months of life with an incurable breast cancer.
How and When?

• As The New Yorker summarized the current situation in a recent article on end-of-life issues, “Our medical system is excellent at trying to stave off death with $8,000 a month chemotherapy, $3,000 a day intensive care, $5,000 an hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop.”
How and When?

• This same article further noted that “in 2008, the national Coping with Cancer project published a study showing that terminally ill cancer patients who were put on a mechanical ventilator, given electrical defibrillation or chest compressions, or admitted, near death, to intensive care had a substantially worse quality of life in their last week than those who received no such interventions.”

• “Six months after their death, their caregivers were three times as likely to suffer major depression.”
How and When?

• Many people believe that hospice care hastens death because patients forgo hospital treatments and are allowed high-dose narcotics to combat pain. But studies suggest otherwise.

• In one, researchers followed 4,493 Medicare patients with either terminal cancer or congestive heart failure. They found no difference in survival time between hospice and non-hospice patients with breast cancer, prostate cancer and colon cancer.
Given all this, why aren’t more patients turning to Hospice Care?
It may be that there are just not enough people involved with their care who are able and willing to talk about Hospice Care.
Talking Makes A Difference

• In late 2004, executives at Aetna started an experiment. They knew that only a small percentage of the terminally ill ever halted efforts at curative treatment and enrolled in hospice, and that, when they did, it was usually not until the very end.
Talking Makes A Difference

• In this study, the traditional hospice rules applied – in order to qualify for home hospice, patients had to give up attempts at curative treatment.

• They received phone calls from palliative-care nurses who offered to check in regularly and help them find services for anything from pain control to making out a living will.
Talking Makes A Difference

• For these patients, hospice enrollment jumped to 70%, and their use of hospital services dropped sharply.

• Among elderly patients, use of intensive-care units fell by more than 85%.

• Satisfaction scores went way up.
Talking Makes A Difference

• Two-thirds of the terminal-cancer patients in the Coping with Cancer study reported having had no discussion with their doctors about their goals for end-of-life care, despite being, on average, just four months from death.

• But the third who did were far less likely to undergo cardiopulmonary resuscitation or be put on a ventilator or end up in an intensive-care unit.

• Two-thirds enrolled in hospice.
Talking Makes A Difference

• These patients suffered less, were physically more capable and were better able for a longer period to interact with others. Moreover, six months after the patients died their family members were much less likely to experience persistent major depression.

• In other words, people who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish.
Talking Makes A Difference

- The converse is also true. According to a recent study by researchers at the Mount Sinai School of Medicine, patients with terminal cancer who disenrolled from hospice care had significantly higher rates of hospitalizations – including admission to the emergency department and intensive care unit – than patients who remained under the care of hospice.
- Furthermore, patients who disenrolled from hospice were more likely to die in the hospital than patients who remained with hospice until their deaths.
Talking Makes A Difference

Here are the specific numbers from that study.

✓ 33.9% of the patients who disenrolled from hospice care were admitted to an emergency department, in contrast with only 3.1% of hospice patients.

✓ 39.8% of disenrolled patients were admitted to the hospital as an inpatient, in contrast with only 1.6% of hospice patients.

✓ Disenrolled patients spent an average of 19.3 days in the hospital, whereas hospice patients spent an average of 6.7 days.

✓ 9.6% of disenrolled patients died in the hospital, compared to only 0.2% of hospice patients.
Talking Makes A Difference

• Lastly, the study found that costs of care for patients with cancer who disenrolled from hospice were nearly five times higher than for patients who remained with hospice.
Who Are We?

Weinstein HOSPICE
The Weinstein Hospice

• We are a small non-profit hospice program. Our mission is to provide comfort and the highest quality of care to adults confronting life-limiting illnesses.

• We reflect the Jewish concern for the dignity and uniqueness of each human life. We know that every moment is precious, but we passionately believe that a measure of peace can be part of the dying process.
The Weinstein Hospice

• Although we are a Jewish hospice, we welcome anyone, regardless of race or religion, who wants to be served by a smaller, more intimate hospice program.

• This explains why approximately 40% of our patients over the years have been non-Jewish.
Why Use Us?
Why Are We Better?
Why We Are Better

• Our focus is on comfort care when cure is no longer possible, and our goal is to maximize quality of life for our patients.
• Rather than tell you ourselves why we think we provide a better and more caring level of services, we’ll let those who have used us to assist with end of life issues of loved ones do it for us.
Why We Are Better

• Calling us can be one of the most difficult things a patient or family member will ever do. Just ask Hal Schanker. Hal and his wife Ruth knew this when they called, and they came to appreciate it in a profound way. Here’s how Hal described their experience.
Why We Are Better

• “Thank you for helping Ruth and me through such a difficult and emotional time. Your telling us what was to come, although sometimes jarring, was helpful. And your compassion and care was more important than anything to us. It made her smile just to see you come in the room. I don’t know how you do what you do, but I am eternally grateful for the gift you must have to do it.”
What does Weinstein offer?

• Physical, emotional, social and spiritual support to each patient and family
• Individualized service within the context of Jewish traditions and values
• Bereavement support for families following the death of their loved ones
• Coordinated care among staff, volunteers, patients and families
• Staff availability 24 hours a day, 7 days a week
• A collaborative partnership in care
Who is the Weinstein team?

• Doctors and nurses attend to the patient’s physical needs (e.g., pain and shortness of breath) while social workers provide emotional support for not only the patient but the family.

• Spiritual support and guidance is provided by the chaplain, and volunteers provide assistance with companionship, transportation, life review and letter writing and quilt making, all of which is part leaving a legacy.
Who is the Weinstein team?

• The patient's attending physician who remains responsible for medical decisions
• The hospice medical director who offers medical consultation for symptom control
• The hospice director who manages staff and daily program operations
• Registered nurses who coordinate the care provided by the palliative care team
Who is the Weinstein team?

• Certified nursing assistants who do personal care
• Social workers who provide emotional and family support including counseling, financial guidance and access to community resources
• Compassionate trained volunteers who provide companionship, practical assistance and respite to caregivers
• A chaplain who is available to provide spiritual support
• Other consultants as needed
What about referrals?

• Referrals may come from any source.
• The patient’s physician must approve and sign the hospice admission. Acceptance into hospice is based on the patient’s medical eligibility and the understanding, desire and need of the patient/family for hospice care as reviewed and determined by the hospice admission team.
• In the event Weinstein Hospice does not best meet the patient’s need, referral to the appropriate agency will be suggested.
What about payment?

• Medicare and most private insurance plans have a hospice benefit.
• However, we will provide care regardless of ability to pay.
What Can You Do?
How You Can Make A Difference

• Give us an opportunity to show you that quality of life can happen with hospice care.
• Give us one patient to allow us to show you the difference hospice can make.
• Start thinking about hospice as a therapeutic intervention and not a last resort!
• Get comfortable with talking about options to your patients.
• Give your families permission to talk about what they want.
To make a referral to Weinstein Hospice, call our Lifeline 404-351-1897