



Hospice Care: Making a difference in the lives of the terminally ill

BY POORNIMA JAYARAMAN, SOUTHERN HEALTH EDITOR

Not too long ago, a terminally ill girl in our community had one last wish. She had seen previews of the upcoming Disney movie, 'Brother Bear' and expressed her fervent desire to see the film.

The movie had not been released as yet and the girl had little time left to live.

Pulling out all stops, the staff at the Hospice of Southern Illinois came up with a creative solution, by calling some top executives at Disney. The media giant showed its humane side by making an exception and promptly sent across a pre-release copy of the film.

The girl got her last wish. She saw 'Brother Bear' right before she died.

Understanding what a hospice does

Hospices focus on care, not cure, and concentrate on the quality of life, not the duration. They provide end-of-life care to patients and their families who are facing a terminal illness and are typically given six months or less to live. Care is provided primarily in the patient's home, allowing families to be together, to share the patient's final days in peace, comfort and dignity.

Jim Clindaniel, licensed nursing home administrator and executive director of Family Hospice, a not for profit, locally owned hospice catering to the counties of St. Clair, Madison, Monroe, Clinton, Randolph and Washington, said, "The approach to care in hospice is what differentiates it from a hospital."

According to Clindaniel, "Hospice takes a holistic approach; we try to alleviate the pain and symptoms of the terminally ill and don't worry about finding a cure for the disease. We treat the person and not the disease."

Serving around 180 patients a year, Family Hospice sees a lot of terminally ill patients suffering from different kinds of cancer, heart disease, end stage dementia and ALS (Amyotrophic lateral sclerosis).

In the past the emphasis used to be on curative care or

ADVERTISEMENT

You have a choice in Diagnostic Care

visit us online at
www.cedarcourtimaging.com



4D Ultrasounds

(Gift certificates available)



- State-of-the-Art Health Imaging**
- True high field open MRI (magnetic resonance imaging)
 - Multislice CT (computed tomography)
 - Whole Body Bone Densitometry
 - Xray/Fluoroscopy

- The convenience you deserve**
- Same-day appointments with minimal waiting
 - Fast convenient service
 - Friendly environment
 - Most insurance accepted

Same day reports by
Dr. Douglas Fulk and Dr. James Barron

Entertainment Ultrasounds

\$100.00 includes your choice of either a CD, VHS video tape or 4 (3x5) color pictures.

Additional options can be purchased for \$20/each.

Mention this ad and receive 1 additional option for FREE

1200 Cedar Court
Carbondale, IL 62901

Call

(618) 529-8500

with questions or to schedule an exam

Hours of operation: M-F 8-5



Cedar Court Imaging



nothing at all. With advancements in pain management medications and public support towards the whole philosophy of palliative care, the hospice movement has gained momentum.

To put it briefly, hospice and palliative care neither aims to hasten death nor to postpone death. It recognizes the importance of maintaining a quality of life, not just in the dying stages, but also in the weeks, months and years before death.

"The onus really lies with the patient in choosing a palliative versus a curative path of care," said Chris Adams, director of home health and hospice at the Hospice of the Good Samaritan in Mt. Vernon.

Hospice services

Hospices typically provide a program of care that responds to the physical, emotional, social and spiritual needs of the terminally ill and their families.

Hence hospice visits are determined by the patient's needs; anywhere from everyday, to once a week, depending on what kind of need the patient wants addressed.

People who work in a hospice setting include board certified doctors who specialize in hospice and palliative medicine, registered nurses, nurses' aides, social workers, pastors, chaplains and volunteers.

Hospice staff specialize in pain and symptom management, listen and talk to the patient, discuss the disease process, answer questions on spirituality, offer emotional support, discuss end of life issues, are on call 24/7 and work together to meet each patient's individual needs and wishes.

"We also encourage our patients to get out and do the things they enjoy most, be it fishing, camping or shopping," said Lisa Austin, coordinator of the hospice department at the Hospice of the Good Samaritan in Mt. Vernon.

Families included

"The entire family is admitted in the program. Often families are concerned about the patient and the patient will be concerned about family members," said Deborah Hogg, community education coordinator for the Hospice of Southern Illinois (HSI), Marion Multiple Location.

"Often a family member becomes the primary caregiver and he or she has to deal with a whole array of fears ranging from - Am I caring correctly; to what am I going to do; to how will I live without this person?"

Licensed to provide service in 27 counties in Southern Illinois, HSI is located in Belleville, Troy and Marion. With almost 86 percent of their patients over the age of 75, the hospice served around 1,500 patients of all ages last year and expects to exceed 2000 this year.

"When you multiply the patients we serve with their family members and friends, it's an incredible number of people we have touched in so many ways," said Hogg.

The criteria

There are two requirements in most cases to get admission into a hospice.

* Two physicians need to certify that the patient is terminally ill and has six months or less to live. The patient's personal physician and the hospice physician normally work together on this.

* The patient needs to consent to hospice and palliative care

The importance of volunteers

Volunteers make up a bulk of the hospice workforce. "Most of our volunteers come to us because they had a positive experience of hospice with a family member or friend who was dying and they feel it's their turn to give back to society," said Clindaniel.

Family Hospice employs approximately 27 full and part-time workers. Yet the bulk of their workforce is made up of about 150 trained volunteers. "It's getting harder and harder to find volunteers these days," confessed Clindaniel.

"Volunteers perform random acts of kindness," said Austin. "We even have some volunteers who are husband-wife couples," she said.

Hospices constantly seek volunteers to help them out; whether it involves playing checkers with a terminally ill patient or keeping the patient company for a couple of hours.

Life and death issues

"Often patients give advanced directives to hospice staff," said Tim Corzine, Herrin Hospice social worker for TIP Hospice, a for-profit organization located in Mt. Carmel, Centralia, Anna and Herrin in Southern Illinois alone, with other hospices in St. Louis.

The directives could include how they want to be treated medically, who should have the power of attorney for healthcare decisions, if they want a do-not-resuscitate order in place and what kind of funeral arrangements they desire.

"In our culture many fear death and don't like to talk about it," said Hogg. Hospice staff eases fears with education, counseling and help to make the process as pain-free and comfortable as possible, sometimes by just being there or just a phone call away.

"There are different ways of grieving for different cultures and we are trained to handle people from every cultural background, with sensitivity," said Corzine.

Bereavement services

Often holidays and birthdays hit family and friends the hardest, since the person they loved is no longer around to share the special occasion with them.

"Once the patient passes away, our bereavement coordinator follows up with the family and friends of the patient for the next 13 months, to ensure they are coping all right with the loss," said Clindaniel.

Some statistics

According to Dr. Julie Pietroburgo, (Ph.D.), an assistant professor at Southern Illinois University in Edwardsville and a researcher in the area of hospice care and trends, the average length of stay for a terminally ill patient is about 57 days, with 22 days being the median length of stay.

"The biggest frustration for hospices is that patients don't call them in sooner, when you consider that they are authorized to provide care for six months," she said.

A study published by her questioned if the charitable core of non-profit hospices was being compromised, given the financial pressures they were facing and the fact that traditionally hospices haven't been very good at fundraising and marketing.

"I was pleased to find that hospices recognize funding as a huge issue, but remain very committed to caring for people," said Pietroburgo.

Questions you should ask before choosing a hospice

Deborah Hogg, community education coordinator for the Hospice of Southern Illinois, Marion Multiple Location said one should ask friends and physicians for any hospices they have had a personal and positive experience with. Checking the reputation of the hospice and talking to the hospice program is a good idea.

Hogg had a list of pertinent questions, one should ask before choosing a hospice:

1. How many hospice programs are available in your geographical area?
2. Does the hospice program serve your geographical area?
3. Are they licensed with the State?
4. Are they Medicare approved?
5. Do they accept Medicare, Medicaid or your private insurance?
6. Is the patient billed for any services?
7. Will they continue to provide care if you are admitted to a hospital?
8. Are they contracted with the care center caring for your loved one?
9. How do they schedule visits?
10. How often will the nurse and home health aide visit?
11. Are admissions or week-end visits scheduled?
12. Does the nurse come to the home at the time of death?

Misconceptions

Hospices have long been misunderstood for what they do. Here are some common misconceptions:

* Hospices are meant for those who have a last few days left to live: FALSE

"Most patients are referred when death is imminent and the patient is no longer communicating," said Deborah Hogg, from the Hospice of Southern Illinois, Marion Multiple Location.

Chris Adams from the Hospice of the Good Samaritan, recommends that people with terminal illnesses call a hospice sooner, to take advantage of all the services.

"We like to get in early," said Tim Corzine, from TIP Hospice. "It allows the patient and the family, time for grief and bereavement."

* Once you sign up for hospice care, you cannot travel: FALSE

"We have hospice patients who may want to travel to say Florida to meet a relative," said Hogg. In such a case, the hospice gives the patient all possible information about a local hospice program based in Florida that they can call, if they have a need they would like addressed, while they are out there.

* You cannot change your mind, once you enter a hospice: FALSE

"There really is a lot of flexibility in the program," said Hogg. "If a patient changes his or her mind about palliative care and wants to become aggressive again about a cure, they can easily be discharged from hospice so that they can try a new treatment."

"When the family receiving hospice care has the opportunity to get back to their own home, settle in and the patient's symptoms and pain are controlled, a patient has been discharged for a period until eligibility for readmission occurs," said Hogg.

* Hospices are only meant for adults: FALSE

Hospice/Palliative care is not restricted to just adults, services are available for children and adults of all ages.

* Hospices are only meant for cancer patients: FALSE

Hospice care is recommended for a person suffering from any terminally ill disease, ranging from cancer to a motor neuron disease to congestive heart failure. Palliative care has often been described as "intensive care without the hardware."

The background

The modern hospice is a relatively recent concept that originated in the United Kingdom in 1967, when Dr. Cicely Saunders founded St. Christopher's Hospice - the world's first purpose-built hospice.

According to Dr. Julie Pietroburgo, (Ph.D.), an assistant professor at Southern Illinois University in Edwardsville and a researcher in the area of hospice care and trends, "Hospices are a relatively new phenomenon in the United States and have only been around since 1974."

Pietroburgo's research primarily deals with the organizational transformation in non-profit hospices; the environmental and funding pressures they face and how they respond to them.

"Hospices have seen a tremendous growth and there are more than 3,700 hospices operating in the United States today," she said. "Of these about 63 percent are still non-profit and continue to have a charitable mission of taking care of the terminally ill, regardless of their ability to pay."

Pieroburgo said the entry of the for-profit hospices in the last 10 years has greatly changed the existing dynamic and the major issues facing the non-profits today include how to find the money to continue their mission.

"I was the daughter in the room, watching my mother die," says Cindy Grenfell, RN, CHPN, at the Hospice of Southern Illinois, Marion Multiple Location.

When Grenfell's mother was diagnosed with thyroid cancer in 1989, Grenfell flew down from Washington State to spend the last three months by her mother's side. Pregnant and only 24 years old, she was distraught when she found out that her mother's tumors were malignant.

"The chemo was so strong, it destroyed her blood cells and after a point she couldn't take it anymore," recalls Grenfell. "The hospice service was called in only eight hours before she died, but I remember them being so kind, compassionate and loving."

Becoming a hospice volunteer soon after her mother's death, Grenfell hoped to give back to people what they had given her in her time of need. "But there was still a burn within me and one day, I just quit my factory job, sold my house and used the money for nursing school," she says.

"I've been a hospice nurse seven years now, since I started working at the Hospice of Southern Illinois and I can tell you this: to do this work, you have to have total conviction," says Grenfell.

She calls it a divine intervention of sorts for she knows in her heart that she was called to do this. "I know most of the patients I come in contact with are going to die. While I cannot change his or her impending death, I do know I can make a difference in the way they die," she says.

Get a print copy of *The Southern Health Magazine* every month!

- [Subscribe online](#)
- [View a list of *The Southern Health Magazine* dealers](#)

