



# HOSPICE:

## A COMPREHENSIVE PROGRAM

*When a baby is born, great care, love, and attention are given to the infant, especially during the first six months on earth. It is the philosophy of hospice that, at the very least, people deserve the same care, love, and attention during the last six months they spend on earth.*

—Don Jones, Director of Marketing and Public Relations, Incarnate Word Hospital, St. Louis

**H**ospice's palliative rather than curative approach focuses on enhancing the remaining life of the patient, with emphasis on family communication and encouragement to live life to the fullest. Hospice team members help families mobilize their own resources to enhance the quality of life for all involved.

Founded in 1990, Incarnate Word Family and Alzheimer's Hospice is committed to providing the best possible service to patients and their families through personalized care that meets their physical and spiritual needs. A program of Incarnate Word Hospital, it is the second-largest hospice program in the St. Louis metropolitan area, competing with hospice programs of much larger facilities.

The program is dedicated to growth through community outreach. It began operating in 1991 with six employees, four volunteers, and three patients. Today the hospice boasts 44 professional employees, 6 clerical employees, and more than

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BY JUDI NEUBECKER

100 volunteers. Despite this extraordinary growth in only three years, Incarnate Word Hospice has maintained its goal of providing individualized

**Summary** Having begun operations in 1991 with six employees, four volunteers, and three patients, the St. Louis-based Incarnate Word Family and Alzheimer's Hospice today boasts 44 professional employees, 6 clerical staff, and more than 100 volunteers. The hospice offers a medically supervised home care program in which staff work closely with patients and families throughout the illness and bereavement period.

Using a palliative rather than curative approach, the Incarnate Word Family and Alzheimer's Hospice focuses on enhancing the remaining life of the patient. Patients are enrolled based on their need for care, not on their ability to pay for services.

To meet the unique needs of certain patients, the hospice offers a variety of specialized services, including pediatric, Alzheimer's, and AIDS care. Collaborative efforts with local agencies include cross-training, continuing education, client referrals, and support services.

In 1993 Incarnate Word introduced hospice services to area residential care facilities (RCFs). The program enables RCF residents who develop life-limiting illnesses to remain in the place that they have come to know as home.

In March 1994 Incarnate Word Family and Alzheimer's Hospice opened a branch office in north St. Louis. The new location enables the hospice to serve more people and creates an additional resource for physicians treating terminally ill patients.

Volunteers provide rest breaks for care givers, help with meal preparation and simple housekeeping, run errands, comfort patients and family, and listen when others may find their story too overwhelming.



*Ms. Neubecker is assistant vice president of business development and outreach, Incarnate Word Hospital, St. Louis.*





hospice care to general adult, pediatric, Alzheimer's, and AIDS patients and their families.

### HOME CARE

Recognizing that many people prefer to spend their final time at home, Incarnate Word Family and Alzheimer's Hospice offers a medically supervised home care program. The staff work closely with family members throughout the illness and bereavement period, providing medical care and instruction, ordering necessary equipment, verifying insurance coverage, and providing emotional and spiritual support for the entire family. The staff also make home nursing visits as often as needed. A 24-hour, 7-day a week phone service links the patient and family with a hospice nurse should a problem or question arise.

Spiritual guidance to patients and their families is a vital component of the hospice program. In addition to offering bereavement counseling after a patient's death, the hospice chaplain helps patients and families to cope with the issues involved in death and dying and to affirm each patient's unique spiritual faith. Incarnate Word Family and Alzheimer's Hospice also works closely with various parish nurse programs to provide additional medical and spiritual support to patients and families.

Patients are enrolled in hospice based on their need for care, not their ability to pay for services. Funding is provided through private insurance, Medicare, Medicaid, Incarnate Word Hospital, charitable grants, donations, and fund-raising efforts. Community support and collaboration with related agencies and organizations enable the hospice to meet the patients' needs cost effectively.

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### ALZHEIMER'S HOSPICE PROGRAM

The Alzheimer's Hospice Program, developed jointly with the St. Louis Chapter of the Alzheimer's Association, is the second such specialized program in the nation. The two groups collaborated to provide nurses and home health aides, therapists, social workers, and support staff with a minimum of 24 hours of intense training in the care of Alzheimer's patients. Ongoing education regarding Alzheimer's care is provided quarterly to all staff and volunteers.

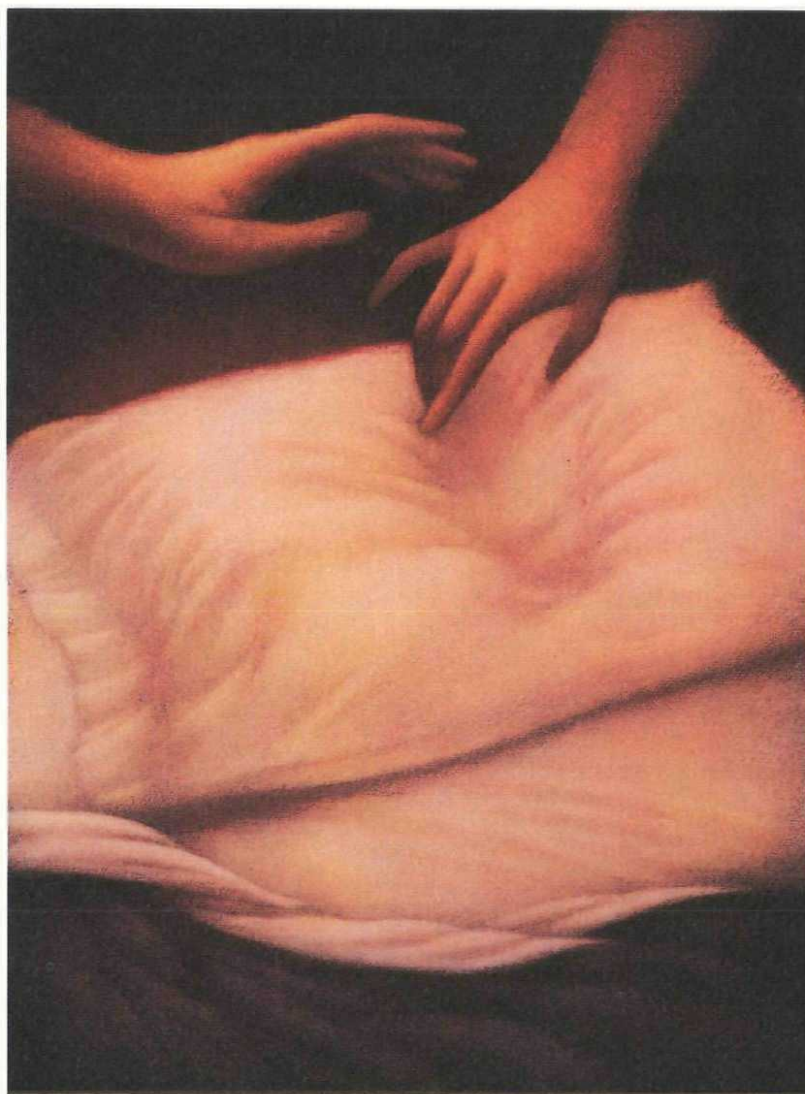
The hospice provides patients with information

## The AIDS Hospice Program stresses the importance of bereavement care.

regarding support programs available from the Alzheimer's Association. Since its inception in May 1992, the Alzheimer's Hospice Program has cared for more than 100 patients suffering from end-stage Alzheimer's disease and related disorders. Services focus on accepting the uniqueness of each family unit and enhancing the quality of the last stage of life for the terminally ill dementia patient and family.

### AIDS HOSPICE PROGRAM

Incarnate Word Family and Alzheimer's Hospice introduced its AIDS Hospice Program in February 1994. The new program has developed a unique relationship with local AIDS-related



Neil Brennan





agencies, including Effort for AIDS (EFA) and Blacks Assisting Blacks against AIDS (BABAA). Hospice staff and volunteers receive special training from these groups in the care of the HIV-positive patient.

Rev. Beth Meyerson, director of client services with EFA, says Incarnate Word Family and Alzheimer's Hospice is a wonderful example of the community responding when needed. "Through front-end education, the hospice helps

AIDS patients understand and prepare for all aspects of death and dying," Meyerson notes. "The more options we have, the more consistent and easy hospice placement will be when the time comes to offer this service to our clients."

BABAA works closely with the AIDS Hospice Program to bring care to the African-American community. The AIDS Hospice Program refers patients to BABAA for support, and BABAA refers its clients to Incarnate Word when hospice

## HOSPICE IN AMERICA: A STATISTICAL PROFILE

### GROWTH OF HOSPICE PROGRAMS

1992-1,935  
1991-1,874  
1990-1,604  
1989-1,529

### NUMBER OF PATIENTS AND FAMILIES SERVED BY HOSPICE

1992-246,000  
1990-210,000  
1989-186,000

### PATIENT STATISTICS

- 53 percent of all patients are male, and 47 percent are female.
- Of the male patients, 68 percent are 65 years of age or older.
- Of the female patients, 72 percent are 65 years of age or older.
- The majority of patients are white (85 percent), followed by African Americans (9 percent), Hispanics (3 percent), and other (3 percent).
- 77 percent of hospice patients die in their own personal residence, 14 percent in an acute inpatient facility, and 9 percent in another institution.
- The average length of patient stay is 64 days, up from 59 days in 1990. Hospice programs, unlike hospitals, are trying to increase the length of stay of their patients.

### HOSPICE SERVICES

- 99 percent admit persons with non-cancer diagnoses.

- 98 percent admit persons with AIDS.

- 90 percent admit terminally ill children.

- 81 percent of hospices offer expanded bereavement programs and services.

- 80 percent provide support group services.

- 67 percent offer memorial services.

- 63 percent provide educational programs to the community.

- 60 percent offer individual and family counseling.

- 43 percent provide crisis counseling.

- 35 percent provide specific children's services.

- 15 percent provide emergency room support.

- In 1992, 78 percent of hospice patients were diagnosed with cancer.

- 10 percent had heart-related diagnoses.

- 6 percent had other diagnoses.

- 4 percent had AIDS.

- 1 percent had renal diagnoses.

- 1 percent had Alzheimer's disease.

### VOLUNTEERISM

- 96,000 volunteers (75,000 women, 21,000 men) provided support to hospice patients and families during 1992.

- Hospice volunteers contributed approximately 5.25 million hours during 1992.

- 59 percent of volunteer hours are provided through direct patient and family care or through components of the bereavement program.

- 41 percent of volunteer hours are in support of administrative aspects of the hospice program.

- Volunteers receive an average minimum of 22 hours of training before they have direct contact with a patient or family.

- The average volunteer provides active volunteer services for three years; 50 percent of volunteers stay six or more years.

- Churches are the most reported avenue for volunteer recruitment (by 94 percent of hospice programs).

### COLLABORATIVE EFFORTS AND BEREAVEMENT SUPPORT

- 63 percent of hospices work with churches to provide bereavement support.

- 55 percent work with hospitals.

- 50 percent work with schools.

- 46 percent work with nursing homes.

- 28 percent provide services and support to community mental health agencies.

- 27 percent work with special organizations such as Widowed Persons Service, American Cancer Society, and Compassionate Friends.

From 1992 *National Hospice Profile* (from data gathered from 1992 National Hospice Census, NHO Provider Member Hospice Personnel Compensation Studies, and NHO membership reporting documents), National Hospice Organization, October 1993, Arlington, VA.





care becomes necessary.

In addition to community agency involvement, the new AIDS Hospice Program stresses the importance of bereavement care. Family members and loved ones receive grief counseling for 13 months after a patient's death. The Bereavement Counseling Department provides individual counseling sessions, support group meetings, opportunity for fellowship, and referral to additional support agencies.

### PEDIATRIC HOSPICE

Although Incarnate Word Hospital's primary focus is providing healthcare to the elderly, the hospice program does accept pediatric patients. Ministering to pediatric patients and their families is different from other areas of hospice care. Pediatric terminal illness often necessitates early admission into the hospice program, and the children may spend more time in the program than adult patients do. Thus the program often offers increased opportunities for individual and family counseling and the development of relationships with patient and family.

Although hospice always focuses on the family unit rather than the patient alone, this is especially true in the case of pediatric hospice care. Hospice patients often have siblings and extended family members who are struggling to cope. Siblings may feel neglected when all free time, money, and energy are focused on the ill child. Each day can be a struggle to remain intact as a family, to deal with the pressures of life that all families face, in addition to the pressures of caring for a gravely ill child, while facing insurmountable medical bills and coping with the grief.

Incarnate Word Family and Alzheimer's Hospice may help families of pediatric patients secure better housing, pay medical bills, or obtain new school clothes for siblings. Sometimes the hospice hosts a special birthday party for a patient or sibling when planning a party is too much for exhausted, financially taxed parents to consider. One parent of a pediatric hospice patient summed up the hospice philosophy when she said that she considers the hospice team a part of her family. She said that she can call them anytime, talk to them about anything, and rest assured that they will always be there for her family, even when illness claims the life of their daughter.

### EXPANDING TO MEET COMMUNITY NEEDS

In March 1994, the hospice opened a branch location in northwest St. Louis County in coop-

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eration with DePaul Health Center. Through expansion and education, the hospice staff can provide care to a greater number of people in a new location. Goals for the new facility include developing a level of spiritual support in the north area that Incarnate Word Family and Alzheimer's Hospice has developed in the southern metropolitan region of St. Louis. The North St. Louis branch gives Incarnate Word Hospital greater opportunity to fulfill its mission of community outreach. The branch office also creates an additional resource to assist physicians in their treatment of terminally ill patients. And the expansion increases the number of St. Louis-area parishes with which Incarnate Word has contact. Ties with local parish organizations give the hospice an opportunity to educate the community on the many services it provides. Parishes are a valuable source of volunteers as well.

### HOSPICE AND RESIDENTIAL CARE

In addition to collaborating with local parishes and agencies, Incarnate Word Family and Alzheimer's Hospice works closely with many skilled nursing facilities, caring for patients in more than 50 nursing homes. The need to educate nursing home staff and clients' families led to the production of a video regarding the natural process of dying. The video provides an overview of hospice and addresses such topics as grief management and bereavement, care for the dementia patient, and pain management.

In 1993 the hospice introduced services to area residential care facilities (RCFs). RCF residents are often overlooked for admission into a hospice program, since they do not live in traditional home settings. Most RCFs are not equipped to care for residents diagnosed with life-limiting illnesses. Without such care, these residents must move to a skilled nursing facility or hospital.

Following contact by the care facility and the resident's physician, the hospice steps in and assists the patient with pain management, medical support, and counseling. After death, hospice provides bereavement counseling for the facility staff and fellow residents. Hospice also assists with funeral expenses and arranges memorial services when patients have no family to tend to these matters. Hospice intervention enables RCF residents to remain in the familiar, comfortable surroundings of home, bolstered by the support of the care givers and friends who have become surrogate family.

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## HOSPICE

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### HOSPICE VOLUNTEERS

Hospice volunteers play an important role in the lives of patients and families. They provide rest breaks for caregivers, help with meal preparation and simple housekeeping, run errands, comfort patients and family, and listen when others may find their story too overwhelming. All volunteers receive a minimum of 20 hours of specialized instruction and are supervised closely by an assigned hospice team member. Those volunteers who work with Alzheimer's or AIDS patients and those who serve as bereavement support staff receive additional, specific training.

Many of the hospice volunteers become involved with the program after a personal experience with hospice through the loss of a loved one. Because of their experience, these volunteers bring a valuable level of understanding and empathy as they help hospice patients and families cope with the challenges of a life-limiting illness.

### THE HOSPICE MISSION

Incarnate Word Family and Alzheimer's Hospice is a living example of the mission of the Sisters of Charity of the Incarnate Word, the hospital's sponsor. Those in need of hospice care can depend on a comprehensive support system to guide them through the challenges of a life-limiting illness. Despite fiscal constraints, hospice achieves its mission of meeting each patient's unique needs through the dedication of a creative and talented team of staff members and volunteers committed to community outreach and growth. The many cards, letters, and personal thank-yous that hospice receives are testimony to the program's success and the importance of giving each person an end to life that is dignified and pain-free. □

## REAL WORLD

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# The Broadway program enhances the mission of St. Francis Health Care Centre.

other places that they would normally visit.

St. Francis Health Care Centre has been an integral part of the village of Green Springs for many years. Community residents are accustomed to seeing people from the facility in town and are supportive of patients and knowledgeable about their needs. This enables patients to practice the skills in a real, yet still somewhat protected, world.

**Module 3: A Small Community** Some patients may need to practice skills, such as shopping in a crowded mall, going to a movie theater, or eating in a restaurant, in environments unavailable in Green Springs. St. Francis has a bus, a van, and several cars for transporting patients when they need to try their independence in a larger community.

**Module 4: Larger Cities** Patients who live in metropolitan areas may need to practice still more special skills in order to be independent. If patients need experience using public transportation and banking or shopping on a busy street, arrangements are made for them to try their skills in their own cities.

### BENEFITS FOR ALL

The Broadway program greatly enhances the mission of St. Francis, according to Sr. Carol Beckermann, OSF, associate administrator of Mission Integration at St. Francis.

"The program helps our patients adapt to their disabilities while increasing their independence and helping them maintain their dignity," Sr. Beckermann says. "Our holistic approach to healthcare deals not only with physical independence, but also with the cognitive and social integration needed to get our patients home again."

Residents of Green Springs believe

the program has helped *them* too.

"It's working well," says Ted Rutherford, branch manager of Croghan Colonial Bank, a participant in the program. "We don't have an automatic door, but we have installed a bell that can be used by a person in a wheelchair. The tellers open the door themselves, and they enjoy the experience of helping."

Patients report that the real-world practice helps them better prepare for the physical challenges they face when they return home.


"You actually see some of the obstacles you'll face when you go home," says Sharon Kidd, a patient at St. Francis. "I went to the hardware part of a store and could see what I wanted in an aisle, but the aisle was too narrow for my wheelchair. It was like 'look but don't touch.'"

"You feel like people are staring at you and you feel very self-conscious at first," she continues. "You wonder if people are just being nice to you because you are in a wheelchair. But the more you're out, the easier it gets. I guess that's how the Broadway program helps the most."

Several other facilities have expressed an interest in the program, according to Baptista.

"The program is good for the patients and the community, and it is low-cost," Baptista says. "Everyone benefits. We consider it a tremendous success." □

*Some information for this article was provided by the following St. Francis Health Care Centre employees: Julie Baptista, director of Occupational Therapy; Tim Hillier, marketing communication specialist; and Wendy Pearce, marketing operations specialist.*

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