

## HORIZON HOSPICE NEWS

# INTRODUCING HORIZON HOSPICE

Horizon Hospice is a new program of care for people who are dying and their families and friends. It offers an opportunity to patients suffering from a life-threatening illness to solve their unique problems and meet their special needs.

The Hospice is operated by a Board of Directors with guidance from an Advisory Board, a team of trained volunteers, and a Medical Director.

The Hospice is also a concept of care which has evolved from the middle ages when "Hospice" meant a resting place for pilgrims. The word comes from the same root as "Hospitality" and has come to mean a special system of care for dying patients. The modern Hospice combines superior medical care, especially alleviation of pain and control of symptoms, with specialized attention to all the patients' needs: spiritual, psychological, practical, and emotional.

This concept of care is expressed to patients by Dr. Cicely Saunders, founder of St. Christopher's Hospice as "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die."

Horizon Hospice will also someday be a place for people who cannot die at home, but would like an alternative to dying in a hospital. Board members have visited other Hospices to learn what style of facility works best. They have also set up a "Building Committee" to create a long-range plan for design, funding and operation of a Hospice building.

## HISTORY

Horizon Hospice evolved under the leadership of Mrs. Ada Addington, President, a veteran volunteer at Children's Memorial Hospital and Cook County

Hospital. She had been interested in beginning a Hospice in the Chicago area for several years and in 1977 began meeting regularly with Sharon Bunyan, a lawyer, Dr. Francis Duda, a pediatrician, and Rev. J. Wilson Reed, a priest. In 1978, they recruited a Board of Directors, completed the necessary legal tasks of incorporation and filing for a tax exemption, and began open meetings.

The Board of Directors did extensive research into the literature on death and dying as well as the operation of a successful Hospice. They went through an in-depth training course and began to work with patients on an individual basis. Working committees were set up, volunteer training begun, and funding proposals written and submitted.

## GOALS

Horizon Hospice has ten goals:

1. To provide a means through which citizens might do something that matters for those in the last stage of life and for those who are losing someone whom they love.
2. To enable the dying person to be at home, cared for by family, friends, and/or the Hospice volunteer and professional staff.
3. To provide support and care for the spiritual, psychological, emotional and practical needs of the dying and those they love for as long as that is needed.
4. To be with the dying so that they will not be alone.
5. To provide information and referrals for the patient and family for whatever needs there might be.
6. To enable the dying and their loved ones to have as much control over their lives as possible.
7. To answer every question as truthfully as possible.

8. To relieve pain and to control symptoms through the use of modern medical care.

9. To refuse help to no one, no matter what the financial situation.

10. To provide a caring place for the dying to live in if they cannot be maintained at home.

## PEOPLE

Horizon Hospice is the people who choose to do the work. The Hospice Board of Directors has recruited a dedicated group of volunteers who have given their time to make the Hospice a reality. Some have given their professional skills, such as doctors, nurses, psychiatrists, artists, secretaries, lawyers, architects, photographers, social workers, librarians and teachers. Others have given their volunteer skills, time, and love in many different ways. Still others have made a financial contribution to help Horizon Hospice hire a Medical Director and launch the volunteer training program.

## VOLUNTEER TRAINING PROGRAM

Horizon Hospice has begun training volunteers for work with Hospice patients. The training course was designed by Martha Mabie, a veteran volunteer, Harriet Kirby Lewis, a psychiatric social worker, and Susan Holinger, a registered nurse. If you are interested in volunteering with Horizon Hospice, please fill in the response form on the back of the newsletter.

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# LONDON HOSPICE VISIT

## ST. CHRISTOPHER'S AND ST. JOSEPH'S

### BACKGROUND

The last week of January Horizon Hospice Board members and friends escaped Chicago's record-breaking winter to visit two Hospices in London, England: St. Christopher's in suburban Sydenham, southeast of London, and St. Joseph's in the East End. Both of these are considered among the oldest and best models of Hospice care in the world.

We received this rare opportunity through the efforts of Dr. Whitney Addington, Chairman of Pulmonary Medicine at Cook County Hospital. When he was invited to present a paper to the Royal College of Physicians in London, Dr. Addington arranged for our group to tour the two world-famous Hospices and interview their staff.

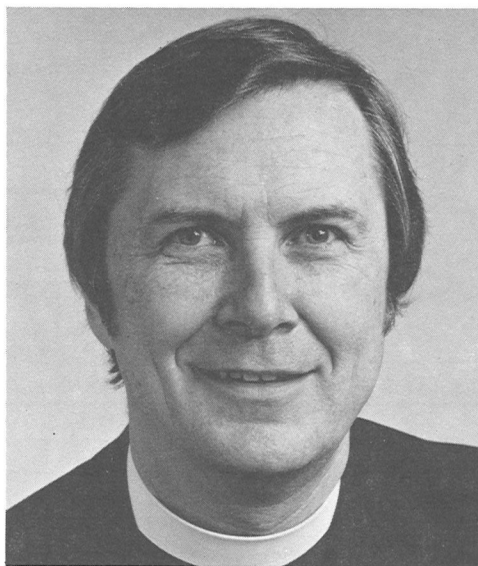
The physicians went on rounds with Dr. Mary Baines at St. Christopher's while the rest of the group toured the Hospice with Miss Summers, Coordinator of Studies. At Joseph's, Sister Paula, Matron (Head of Nursing), and Dr. McKerrow told us the history and philosophy of their Hospice. Then we were able to tour the buildings and chat with some of the patients.

In both Hospices, we were refreshed by their English hospitality and inspired by their examples.

Visiting the London Hospices were Ada Addington, Dr. Whitney Addington, Joan Flanagan, Rev. J. Wilson Reed, and Robert Worster from Horizon Hospice, as well as Ann Morris and Kathy Wirtz from In-home Health-Care North, and Carol Huige and Dr. Robert Sewell from the Hospice at Rogers Memorial Hospital in Wisconsin.

This visit was part of the intensive research done by the Horizon Hospice Board during the last year. To help plan our Hospice in Chicago, we have visited six Hospices to see first-hand several different examples of Hospice care. These were the Palliative Care Unit at Royal Victoria Hospital in Montreal; The Connecticut Hospice at New Haven; Hospice at The Rogers Memorial Hospital in Oconomowoc, Wisconsin; The Hospice of St. Paul at Bethesda Lutheran Medical Center in St. Paul, Minnesota; The Hospice of Marin in San Rafael, California; and the Elisabeth Kubler-Ross Hospice in Clearwater, Florida. In all cases, the staff and volunteers at these hospices were extremely generous in sharing their experience and encouragement.

Following is Rev. J. Wilson Reed's personal account of the London visit.



### HOSPICE VISIT by Rev. J. Wilson Reed

London in January isn't everyone's cup of tea! Much to our delight there was no snow on the ground, just green grass and unfortunately a growing number of garbage bags (the "dustman's strike," you know).

One of the reasons for this trip was for members and friends of Horizon Hospice, Inc. to visit two of London's best known hospices, St. Joseph's (founded in 1905 by the Sisters of Charity from Ireland) and St. Christopher's (founded in 1967) by Dr. Cicely Saunders, O.B.E.

Although located in different kinds of neighborhoods, these hospices share more than a mutual hospice philosophy. Dr. Saunders spent seven years working at St. Joseph's before she opened St. Christopher's. Both buildings are "post-war", done by the same architect, and feature a lot of glass to help bring the outside in. St. Christopher's setting is more "suburban" than St. Joseph's. But Sister Paula, Matron of St. Joseph's, assured us that their guests—many of them "cockneys"—prefer to look out on the gas works and at the red two-deckered buses with which they are familiar. During WW II they were evacuated to Bath (on 24 hours notice) and were bewildered by the grass and trees and stillness.

### PRIORITIES

Both hospices give highest priority to (1) pain control, particularly in terminal malignant diseases; (2) the personal needs of the patient as well the family or close friends involved; and (3) religion or the spiritual needs of the patient. These can hardly be separated. Can you imagine yourself in constant pain? How can you possibly tell someone about your will or how much you love him (her) or even find out if Fido is getting his daily walks? And certainly if you are weakened

and depressed by pain, how can you even think about what your faith means or doesn't mean at such a time. These subjects are not so easy when a person is in good health.

The doctors who were with us were impressed, indeed excited by the sophisticated use of drugs at both of these hospices. There are no beds surrounded by beeping machinery or gurgling tubes. Medication is almost always taken by mouth and is taken to treat the symptoms. We were reminded that the purpose of the hospice is not to cure the disease. There is a place for that. At this stage medication is given to keep the patient free from pain and yet aware of what's going on, and, in many cases, able to participate in the community life of the hospice.

Every Thursday St. Christopher's opens their "Pub" for patients as well as visitors. Miss Summers, co-ordinator of education and the speaker's program, assured us in best Anglican fashion, "It's part of the program we're all very keen on!"

### FAMILY QUALITY

Another innovation at St. Christopher's is a day-care center for children of the staff. There is nothing sepulchral about a building where youngsters bound down the corridor to enjoy their recess on the playground. Someone even had a dog on a leash. This is not by accident. Children have a wonderful way of just being themselves in such situations. They bring a family quality to the hospice which helps to make it more like a home and less like a hospital. St. Christopher's also has a wing for the elderly and rooms for those with advanced neurological diseases. There is also an educational building just down the block. Persons from all these groups, including the children, often meet each other—in the garden in good weather—in the dining room, or in the crafts center at certain times of the day.

St. Joseph's new wing is called Heenan House and offers residential rehabilitation for the physically handicapped. Some come and go as out-patients. Others stay for short terms because they need intermittent relief for themselves and/or those caring for them. (Speaking of "relief," St. Christopher's calls Monday, "Family Day Off," and except for emergencies, insists that family and other loved ones take a break for the good of the patient and for themselves.)



Ada Addington, Miss Summers and Father Reed at St. Christopher's. Miss Summers observed, "Generally, on the subject of cancer, Americans tell too much too soon, while we British tell too little too late."



## HOSPICE VISIT (continued)

We were surprised to learn that the "average stay" in a hospice is twelve days. But averages have to be explained. In many cases a Domiciliary team (visiting nurses) have made home visits for months, and the patient may have been able to come to the hospice for treatment as an out-patient, always being invited to have "a cup of tea and a little visit." On the other hand, some live in the hospice for months. Sister Paula seemed to know every guest by name and could introduce us, in her gentle Irish way, with bits of biography: "This dear lady SAW Queen Victoria!"

Something one never forgets in a hospice is that these people are very sick and dying. Some are up in years. Cancer plays no favorites. There are also teenagers and young parents. No attempt is made to pretend that they are going to recover, but each day is seen as an opportunity to open new doors of self-discovery. Each person is treated as a unique individual. Loving to the end, no matter what, is the key. There is the pervasive belief that the last days of our life can be in some ways the richest.

## SPIRITUAL CONTEXT

Both St. Joseph's and St. Christopher's do their work in an abiding religious or spiritual context. Dr. T.S. West of St. Christopher's writes in *Frontier*: Winter 1974: "Our foundation is simply Christian; we believe that death is not the end, because Christ has gone through this for us too." There are chapel services and daily prayers. Commendatory prayers are said by the nurse at time of death. The clergy come and go. Not just officially. We like to have them...I call it...untidily about!" says Miss Summers.

But there is no discrimination made on the basis of "creed, cult or color." No one is "preached at" or coerced in any way. No "death bed confessions" urged. There are articles available in St. Christopher's lobby on Jewish and Muslim teaching concerning

## VOLUNTEERS

by Martha Mabie, Co-Chairperson Volunteer Committee

Volunteers are the heart of Horizon Hospice. They bring their caring, intellectual curiosity, flexibility, and talents. The Hospice gives them the chance to work with a varied group of people, the training to learn new skills on how to deal with people, the education on the area of death and dying, and the opportunity for leadership. I know this program will excite an outstanding group of volunteers and they will be of enormous value to Horizon Hospice because they come to it with enthusiasm, looking forward to new experiences and challenges.

Volunteering has always been a stimulating, educating, and satisfying experience for me. It is an important part of my life. How interesting to reflect on twenty years of volunteer service, and realize that I am looking forward to another twenty with anticipation, and enthusiasm!

My first volunteer experience was at the Northwestern Hospital Speech Clinic. Over the years I have enjoyed volunteering for both the Northwestern Hospital social service team and the Evanston Hospital child care center. As my children were growing I worked with the Junior League, the local community chest, Sunday school, cub

scouts, the school paper, and several political candidates.

My husband and I both serve as trustees for the Hadley School for the Blind. In fact, one advantage of volunteer work is that it gives you the chance to do meaningful work with your own family and friends at the same time that it introduces you to many new people.

The skills I have learned as a volunteer have enriched my life and helped me to accomplish difficult tasks. I have learned concrete skills such as interviewing, writing, public speaking, recruiting, and motivating.

Volunteering has given me the freedom to create new concepts, generate new processes, and perform new tasks. Best of all, it has taught me to make sound decisions and create productive schedules. When thirty phone calls a week-end is not unusual, you learn to manage your time and get things done!

For me the most important asset has been the interaction with people which has enriched my life. I have learned how to listen to people, how to co-operate with colleagues, how to organize new members, and how to motivate volunteers. Because working with people is the most important part of volunteering for me, all of these skills have added immeasurably to my life. I am sure that twenty years from now, in 1999, the Horizon Hospice volunteers will also be able to look back on a volunteer experience which added an extra dimension to their lives.

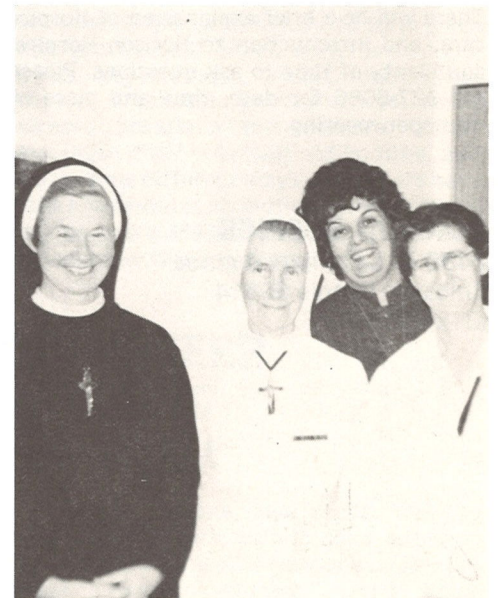
death written by representatives of these traditions. Every attempt possible is made to reach the patient where he or she is in such matters.

"People are not always so far away from faith as we may think," writes Dr. Cicely Saunders, "though we may have to recognize it by seeing signs rather than by hearing explicit verbal confessions of faith. At such a moment the quality of time is so much more important than its length, and the dying are able to live through what seems the experience of a lifetime in a few short weeks."

In an article reprinted from *The Nursing Times*, Nov. 26, 1965, Dr. Saunders tells two unforgettable vignettes. "Seventeen years ago a young Pole died and left me 500 pounds to be 'a window in your Home.' This was the very beginning of St. Christopher's. I also remember his saying, 'I only want what is in your mind and in your heart.' This was echoed years later by another Pole who said to us, 'Thank you. And not just for your pills but for your heart.'"

## NEXT ISSUE:

**The Horizon Hospice Team:** Who it is, what it does, and how it works. A doctor, a nurse, a minister, a social worker, and a volunteer tell why they are involved.



Left to Right: Mother General, Sister Paula and Doctor McKerrow of St. Joseph's Hospice with Ada Addington, President of Horizon Hospice. Doctor McKerrow explained, "If you can't treat what's causing the pain, you treat the pain. Watch out for even a niggles of pain! We always assure our patients that 1) You won't experience pain, and 2) we won't leave you alone. Never wash out hope."

# HORIZON HOSPICE INTEREST FORM

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

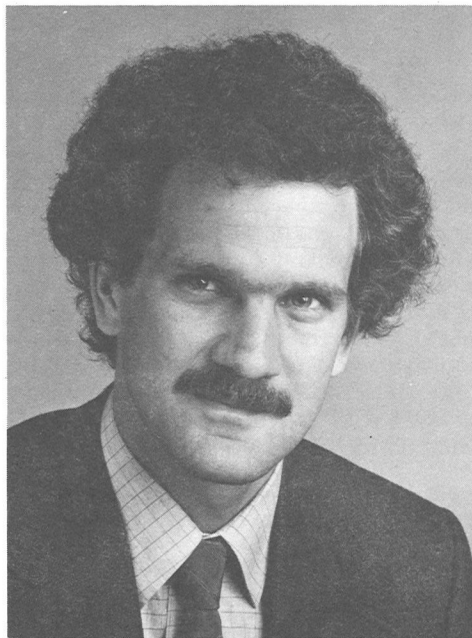
Telephone: Home: \_\_\_\_\_ Office: \_\_\_\_\_

**PLEASE HELP US BY:**

- Volunteering your time and talent
  - Clerical
  - Professional (Specify) \_\_\_\_\_
  - Good Neighboring (sewing, dogwalking, letterwriting, etc.)
  - Fundraising
  - Other (Specify) \_\_\_\_\_
- Giving financial support. Your contribution to Horizon Hospice is tax deductible. Please make your check payable to: Horizon Hospice. Return this form by mail to Horizon Hospice.

## MEDICAL DIRECTOR

Horizon Hospice is proud to announce that Dr. Michael Preodor has become its first Medical Director. Dr. Preodor is an internist currently in private practice in Chicago. He has been accepted for the special training program under the direction of Dr. Balfour Mount at the Palliative Care Unit at Royal Victoria Hospital in Montreal in September. "I am honored to be a participant in this world famous training program, said Dr. Preodor. "I look forward to the opportunity for first hand study of modern Hospice care, pain management, and symptom control!"



Michael Preodor, Medical Director, Horizon Hospice

## OPEN MEETINGS

If you would like to learn more about Horizon Hospice and Hospice care in general, please attend one of the Open Meetings held every month. Newcomers are welcome. There will be a brief explanation of Hospice care, and introduction to Horizon Hospice, and plenty of time to ask questions. Please call 327-8086 for date, time and place of next open meeting.

## NEWS

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