

■ HORIZON HOSPICE SERVICES

9

■ CAREGIVER/FAMILY ISSUES ■ HORIZON HOSPICE SERVICES

7

■ TEAM BEHIND THE SCENE ■ PATIENTS AND SETTINGS

5

■ PURPOSE OF HORIZON HOSPICE ■ THE HORIZON HOSPICE TEAM

3

■ CONTENTS

1



HORIZON HOSPICE

PATIENT AND  
CAREGIVERS  
HANDBOOK

# INTRODUCTION

*HORIZON HOSPICE began in my living room in 1978 with the help of a clergyman, a physician, and an attorney. We never imagined that starting an organization would entail so much work or be so gratifying.*

*We are constantly amazed by the ingenuity of our families, the dedication of our volunteers and staff, and the generosity of those who have contributed funds to our work.*

*We hope this Handbook will be helpful to you because we know that caring for a very ill person can be difficult, but we at HORIZON HOSPICE, hope you, too, will experience some very special rewards.*

*Sincerely,*



Ada Addington

Founder and Chairman of the Board

# CONTENTS

- **PURPOSE OF HORIZON HOSPICE...**Page 2
- **THE HORIZON HOSPICE TEAM...**Page 2,3&4
  - Nurse Coordinator
  - Primary Nurse
  - Medical Director
  - Social Worker
  - Volunteers
  - Speech/Physical/Occupational Therapists, Nutritionist
  - Home Health Aide
  - Pastoral Care
- **TEAM BEHIND THE SCENE...**Page 4
- **PATIENTS AND SETTINGS...**Page 5
  - In-Home Patients
  - In-Hospital Patients
  - Patients in Congregate-Living Facilities
- **CAREGIVER/FAMILY ISSUES...**Page 6
  - Care of Patient
  - Exhaustion
  - Expenses
  - Death
  - Funeral Arrangements
- **HORIZON HOSPICE SERVICES...**Page 7,8&9
  - Pain and Symptom Management
  - Instruction and Guidance for Family and Friends
  - Providing Care at Home
  - Delivery of Medical Supplies, Equipment and Medication
  - Medicare, Medicaid, Insurance
  - Bereavement Services
  - Library
- **NAMES AND PHONE NUMBERS...**Page 10

■ CONTENTS

■ PURPOSE OF HORIZON HOSPICE ■ THE HORIZON HOSPICE TEAM

■ TEAM BEHIND THE SCENE ■ PATIENTS AND SETTINGS

■ CAREGIVER/FAMILY ISSUES ■ HORIZON HOSPICE SERVICES

■ HORIZON HOSPICE SERVICES

■ **PURPOSE OF HORIZON HOSPICE**

*Horizon Hospice exists to provide comfort and preserve dignity for people with a disease they are not expected to recover from. Horizon Hospice offers solace, support and understanding for families and friends involved in caregiving.*

■ **THE HORIZON HOSPICE TEAM**

Through the years, Horizon Hospice has learned that, like members of a family, no two patients are ever alike. Care Plans for patients and their caregivers, therefore, are styled according to specific needs.

To fully comprehend how the Care Plan is developed and how it will work, it is important to understand who the Horizon Hospice team is, what roles they will play, and how they can be expected to help patients, their families and/or caregivers.

■ **THE HORIZON HOSPICE TEAM YOU WILL MEET:**

**Nurse Coordinator**

The Nurse Coordinator usually makes the initial visit. He/she is ultimately responsible to set up the Care Plan, coordinate the Horizon Hospice team, and will stay current with the case. The Nurse Coordinator may not visit on a regular basis but will assign a Primary Nurse.

*Nurse Coordinator agenda on initial visit:*

- To determine the primary Caregiver, and to discuss that role in the patient's care.
- To interview the patient and to determine how Horizon Hospice can best proceed medically.
- To consult with the patient and caregiver to determine what needs - physical, psychological and practical - Horizon Hospice can address.
- To leave the following:
  - \* Consent forms
  - \* Insurance election statement

- \* Living Will and/or Durable Power of Attorney
- \* Medication forms to record the administration of medication
- \* Folder with pamphlets, brochures relating to Hospice and patient/family care
- \* Phone numbers of Horizon Hospice team and other people important to the case (see the last page of this booklet)
- To devise, from the above information, a Care Plan which will be followed by the Horizon Hospice team.

**Primary Nurse**

This person is responsible to visit on a weekly basis, or as necessary, to monitor the patient's condition. This Primary Nurse will do a complete physical examination of the patient and report significant changes to the patient's doctor and the Horizon Hospice Medical Director.

**Medical Director**

This person is a doctor who will make one visit and, from then on, only if there's a specific need. If patients have their own physicians, the Horizon Hospice Medical Director will work with them. If not, the Horizon Hospice Medical Director will serve in that capacity.

**Social Worker**

This person makes a home visit to assess patient's/family's needs and will follow up as appropriate.

**Volunteers**

One or two volunteers will be assigned to the case. Horizon Hospice volunteers are of all ages and backgrounds who share one common goal: to help people when they need it most. All volunteers are specially trained and supervised throughout their involvement.

Volunteers will visit or telephone at least once a week, and, with the patient and caregiver, try to determine how they can best help out. Their services range from listening to concerns, helping with weekly shopping, sitting with the patients while the caregiver takes a breather, to helping formulate funeral arrangements. Volunteers are the members of the Horizon Hospice team who stay involved with the caregivers after death of the patient.

**Speech/Physical/Occupational Therapist, Nutritionist**

These people do not visit on a regular basis but are available to set up a program if it's necessary.

**Home Health Aide**

A home health aide will be provided if the Nurse Coordinator determines it is necessary. Home health aides offer assistance with personal care, feeding and light housekeeping.

**Pastoral Care**

Horizon Hospice has a chaplain and can coordinate services from clergymen of every faith to serve the patients' needs. They visit, however, *only if requested* by the patient or family.

■ **THE HORIZON HOSPICE TEAM BEHIND THE SCENE**

Horizon Hospice headquarters are out of the Stone Medical Building, 2800 North Sheridan Road. To handle the 40 or more cases it usually serves at any one time, a dedicated back-up team works to support the Horizon Hospice team involved in direct patient care. This behind-the-scenes team consists of:

Volunteer Coordinators, Secretaries and Support Staff, Staff Development Director, Program Director, Finance Director, and Executive Director

PATIENTS AND SETTINGS

■ **PATIENTS AND SETTINGS**

Horizon Hospice serves patients in three kinds of settings: in home, in-hospital and in congregate-living facilities. During the course of an illness, there may be a need to change settings. Regardless of the setting, Horizon Hospice will continue to follow the patient, and adapt its Care Plan accordingly.

**In-Home Patients**

95% of Horizon Hospice care is delivered to people in their own homes. Such an arrangement, when possible, is usually preferable since family and friends can participate in the day-to-day care of the patient, offering the kind of love and spiritual support so vital to everyone. Also of utmost importance, it helps to allow patients to manage their own deaths.

**In-Hospital Patients**

Sometimes patients' pain or other symptoms cannot be managed at home, and there is a need to be hospitalized. Horizon Hospice has contracts with St. Joseph, Northwestern and Louis A. Weiss Hospitals. These contracts insure that the Horizon Hospice Care Plan continues without interruption should a patient be moved between settings. If, however, a patient wishes to be admitted to any other hospital, Horizon Hospice will endeavor to coordinate the Care Plan with the non-contracted hospital, but may ask the primary caregiver to keep the Horizon Hospice team informed.

*If it is necessary in an emergency to transfer a patient to any facility, it is very important to notify Horizon Hospice first.*

The Primary Nurse or nurse on 24-hour call will assist with the transfer, i.e., call ambulance, notify facility, etc...

- **Patients In Congregate-Living Facilities**  
(i.e., Nursing Homes, Bonaventure House, Retirement Centers) - If patients reside in congregate-living facilities, and need Horizon Hospice services, they can expect us to provide the same services as if they were at home. The facilities' rules and/or regulations need to be considered, however, in the overall Care Plan.

#### ■ CAREGIVER/FAMILY ISSUES

Although Horizon Hospice serves about 40 patients at any one time, each patient remains unique and very important. Some patients and/or caregivers and families may be more needy than others in that there may be small children in the home; or, there may only be elderly caregivers with limited physical resources; or, there may be caregivers who work; or, there may be extreme poverty. While the Care Plan tries to account for specific needs, all primary caregivers and/or families can expect to deal with the following issues:

- **Care of Patient**  
The Care Plan and discussion with the Nurse Coordinator should help to set up the day-to-day care for the patient. (A medical chart to be marked when medication is administered should be filled out.)
- **Exhaustion**  
Sometimes even the sturdiest of caregivers needs relief, especially to get a good night's sleep. Horizon Hospice staff and volunteers can relieve caregivers for brief periods and can help caregivers to arrange for additional help at the patient's/family's expense.
- **Expenses**  
Although Horizon Hospice provides most basic medical equipment, it does not provide everything. Medical and personal needs for the patient can be determined with the

## SERVICES

Nurse Coordinator. Many of these expenses may be paid by Medicare, Medicaid, or insurance. See page 8 for more detail.

- **Death**  
The signs and symptoms of approaching death are important to know. A pamphlet on this subject is enclosed in your folder. When death occurs call Horizon Hospice (312)871-3658, and ask for the nurse on call. *It is not necessary to call the police or 911.*
- **Funeral Arrangements**  
One of the greatest assets of hospice involvement is that the patients and their caregivers/families, if they wish, can discuss openly the impending death. Horizon Hospice has found that it is very important, in most instances, to plan funeral arrangements. Also, if the patient and/or caregivers and family care for it, a minister, priest or rabbi may be called in before the patient dies to discuss spiritual issues and even plan funeral or memorial services. The Horizon Hospice volunteers are prepared to help with these procedures, to help find a funeral home and to help prepare for the eventual death, so that when it comes, it can be as peaceful and serene as possible.
- **HORIZON HOSPICE SERVICES**  
Horizon Hospice takes its involvement with each case very seriously and strives to implement every detail of the Care Plan which is filed and constantly updated in the office. Daytime weekly meetings with office personnel, at the direction of the nurse coordinator, are held to review each case; and evening bimonthly meetings with volunteers, volunteer coordinators, medical director, and professional staff are held to determine the overall delivery of Horizon Hospice's services.

*The following is a list of Horizon Hospice services:*

**Pain and Symptom Management**

This issue usually takes precedence over all other issues. Between the Horizon Hospice professional team, and the patient's physician, complete pain management is usually possible.

**Instruction and Guidance for Family and Friends Providing Care at Home**

Since needs may change as the patient's condition changes, Horizon Hospice volunteers, nurses and other team members are always available to discuss how best to meet these challenges, so that they do not become overwhelming.

**Delivery of Medical Supplies, Equipment and Medication**

These items will vary with the specific needs of each patient.

**Medicare, Medicaid, Insurance**

Horizon Hospice has found that most of its services are covered by one of these payors. The cost of providing hospice services to Horizon patients and families is well over \$100.00 per day. Most of these services are covered by Medicare, Medicaid, and private insurance. Billing insurance carriers for services is made as easy as possible for hospice patients and families. During the initial visit the Horizon staff will verify the name of the patient's insurance carrier and his/her identification number, then prepare and submit any necessary claim forms. If a patient's insurance is subject to coinsurances, deductibles and copays, Horizon will bill patients directly for their share. If the patient has no insurance for hospice care, the social worker will do a financial assessment and the patient will be billed according to a sliding fee scale.

**Death and Funeral Arrangements**

A pamphlet detailing death and its symptoms is enclosed in the Horizon Hospice folder. Discussing these issues beforehand makes the eventual death much more serene for everyone.

**Bereavement Services**

Following the busy involvement before, and right after death, the caregiver and/or family are often left feeling very empty. Not only must they deal with the loss of their loved ones, but also a great contrast from a busy to a quiet time. Horizon Hospice volunteers who become involved from the beginning of the case will continue to stay involved through these trying times, phoning, and/or visiting as seems appropriate. Horizon Hospice also offers a monthly bereavement support group to those interested.

**Library**

In the Horizon Hospice offices, there is a library which consists of articles, pamphlets and books relating to hospice issues for people of all ages. This library is always available to our patients, their caregivers and/or families.

Additional information on the following topics is available by calling the Horizon Hospice office or asking any members of the Horizon Hospice Team:

- Helpful Hints for Bedside Care
- Description of On-Call Services
- Nutrition
- Massage
- AIDS Infection Control-Universal Precautions
- Living Will and Durable Power of Attorney forms
- Pain Control
- Signs & Symptoms of Approaching Death
- Medicare Hospice Benefits
- Hospice Volunteering
- Charitable Giving
- Grief and Bereavement

**NAMES AND PHONE NUMBERS**

**HORIZON HOSPICE (312) 871-3658**

Nurse Coordinator \_\_\_\_\_ **871-3658**  
Phone \_\_\_\_\_

Primary Nurse \_\_\_\_\_ **871-3658**  
Phone \_\_\_\_\_

Primary Physician \_\_\_\_\_  
Phone \_\_\_\_\_

Hospice Physician \_\_\_\_\_ **871-3658**  
Phone \_\_\_\_\_

Hospice Volunteer \_\_\_\_\_  
Phone \_\_\_\_\_

Hospice Volunteer \_\_\_\_\_  
Phone \_\_\_\_\_

Pharmacy \_\_\_\_\_  
Phone \_\_\_\_\_

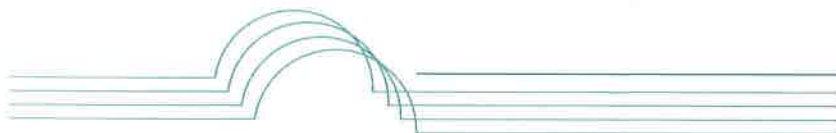
Ambulance \_\_\_\_\_  
Phone \_\_\_\_\_

Funeral Home \_\_\_\_\_  
Phone \_\_\_\_\_

Friend \_\_\_\_\_  
Phone \_\_\_\_\_

Friend \_\_\_\_\_  
Phone \_\_\_\_\_

Friend \_\_\_\_\_  
Phone \_\_\_\_\_



**HORIZON HOSPICE**

STONE MEDICAL BUILDING

2800 North Sheridan Road/Chicago, Illinois 60657-6108