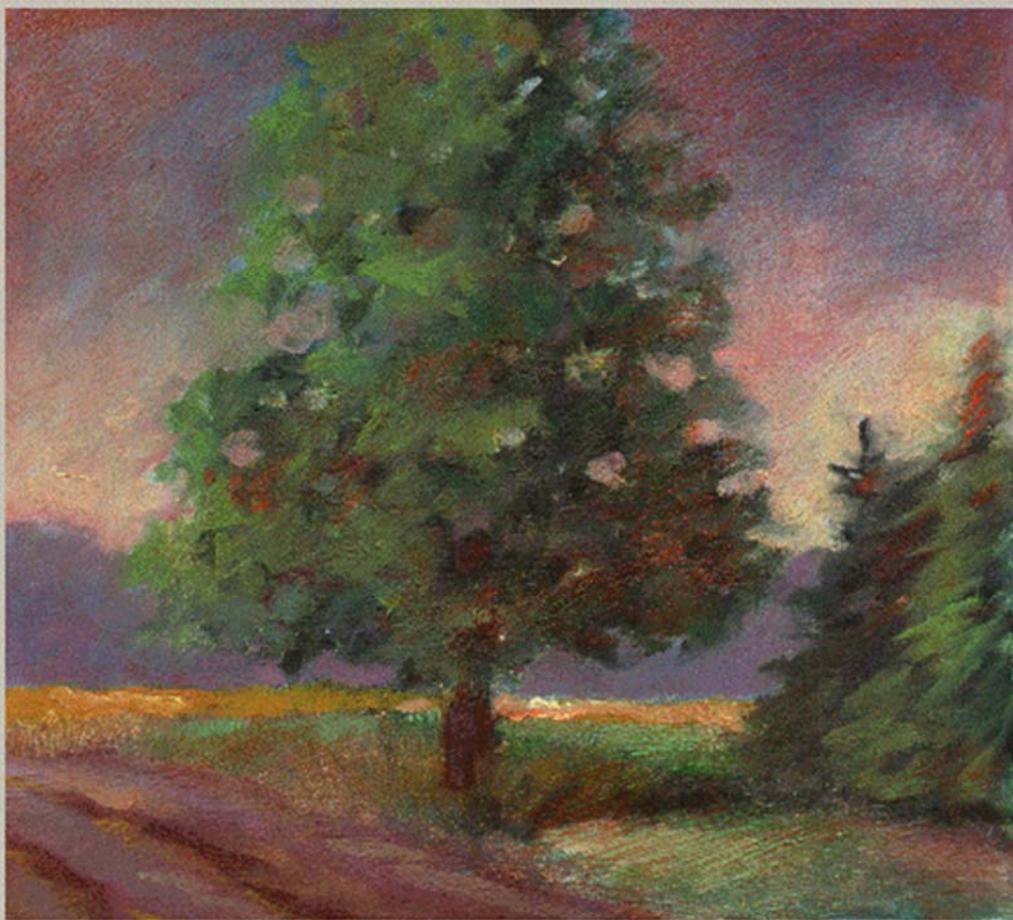


Because nothing is More important  
than your loved one's care...

## **The Hospice Patient's Alliance Family Guide to Hospice Care**

**(What Most Hospices Won't Tell you!)**



**A Hospice Patients Alliance** Publication  
[www.hospicepatients.org](http://www.hospicepatients.org)  
by Ron Panzer - Executive Director

## **Inside Cover Page**

The author and publishers have made a conscientious effort to ensure that the information and data in this book are accurate and up-to-date at the time of publication. However, since the regulations governing health care and hospice in particular may be changed by Federal and State governments, readers are advised to check with official government publications of the respective statutes governing hospice. How to find these statutes is explained in the section on the laws governing hospice..

Hospice Patients Alliance, Inc. is a nonprofit consumer advocacy-oriented charitable organization dedicated to the promotion of quality end-of-life care and hospice care. We serve the general public by informing and assisting terminally ill patients and their families in getting the very best health care available. We are not owned or controlled by any hospice agency, hospice organization or lobbying group.

We reveal what no hospice agency, organization or lobbying group will tell you ... the realities of modern day hospice care ... from the best to the worst, without holding back. For more information, write to us at the address below. We welcome your feedback and questions.

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## Copyright Page

Hospice Patients Alliance Family Guide to Hospice Care  
(What No Hospice Will Tell You!) by Ron Panzer

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*THE HOSPICE PATIENTS ALLIANCE FAMILY GUIDE TO HOSPICE CARE*

ISBN 0-9677045-0-2

# READ THIS BOOK BEFORE YOUR LOVED ONE ENTERS ANY HOSPICE!

Get the latest word on such topics as:

MAKING SURE YOUR WISHES ARE FOLLOWED

GETTING THE BEST PAIN CONTROL AVAILABLE

HOW TO AVOID HOSPICE HORRORS

STOPPING HOSPICE EXPLOITATION

KNOWING WHAT YOUR RIGHTS ARE

HOW TO RECOGNIZE AND REPORT HOSPICE FRAUD

WHAT SERVICES THE HOSPICE MUST PROVIDE

Death and dying have been taboo subjects for far too long. Hospice has changed that and it's now "acceptable" to talk about death, dying and hospice care. What's still taboo and little known is the flagrant disregard of hospice patients' rights by licensed hospices! Why did the Federal government even need to start "Operation Restore Trust" to stop Medicare fraud in hospices? Why don't State inspection agencies make sure hospices provide the care that's required? Why do patients continue to suffer needless pain, even in some hospices?

WHAT WILL NO HOSPICE TELL YOU?

Read on for the shocking answers to these and many more questions.

## Book Reviews and Endorsements

What an experienced nurse says about this book:

"As a former hospice nurse I am acutely aware of the untold truths within the hospice industry, and of the unequal care provided, even within one individual hospice. This book will answer all of your questions and, probably many more you didn't know to ask. This is not just a book, it is a manual of your rights!"

"This book explains all you need to know about "how to" successfully utilize hospice services and assure compassionate and effective end of life care for your loved one. The information contained in this book explains how to get the help you need, when your loved one needs it the most. It is a book written specifically for all hospice patients, families, care givers, and even hospice staff." - Anne Greco

What a daughter of a former patient says about this book:

"The Hospice Patients Alliance Family Guide to Hospice Care was an invaluable resource during the time my father was at home in hospice. The clear, detailed information provided allowed my family to make the decisions that were in my father's best interests and which were right for him and us. More importantly, it gave us insight into all aspects of what was occurring, and it prepared us for the very difficult time when his death was inevitable."

"We were able to make him comfortable, play his favorite

music, spend time with him, and finally, to say our good-byes to him; an opportunity I would not have traded for anything in this world. The book helped to get my entire family through what was probably the most difficult period of our lives."

"I am grateful that there is an organization which has the best interests of the hospice patient in mind. I urge anyone who has a loved one in hospice or who is considering using hospice for themselves or a loved one to read this book. The information is priceless." - Linda Reiter, loving daughter.

## **Acknowledgments**

I would like to express my appreciation for all the people who have encouraged me in writing this book: Cathy Koepp Scholler and Anne Greco have been reliable sources of renewed commitment and inspiration. Without their encouragement, this book would never have come into being.

I especially wish to express my gratefulness to my wife Dorothy and son Jonathan who have been very patient in allowing me the time to work on this project.

The families of Denine Ruhoff Sharpe, of Jose Alvarez, and the families of countless other hospice patients (who suffered needlessly even while being cared for by a hospice) have shared their stories with us in the hope that others would experience better hospice care. These families hope that others may avoid the traumatic experiences inflicted upon the dying by those hospice agencies which betray the trust naturally placed in them, at the time of the family's greatest need..

For comments and editorial suggestions, I wish to thank Anne, Rick and Craig. Those families who have contacted us with their questions and feedback have helped us to know what types of information the public needs most.

## **Introduction for 2014 updated version**

It's been fourteen years since this book was first written and much has changed in our society. We have seen what I call "the big push" by those who wish to transform our government and society into something completely other than what it was originally meant to be: a society that preserves, protects and affirms the Constitutional rights of the individual, even within healthcare settings.

The Constitutional rights of every patient and citizen are based upon the Judeo-Christian worldview and the respect for life that is inherent in our Declaration of Independence and the Constitution ("the right to life, liberty and the pursuit of happiness"). These rights are intentionally being threatened by those who do not embrace the values the founding fathers held dear when they formed this nation. These elitists exalt the State and devalue the lives of the individuals, especially the very elderly, disabled, chronically ill and weak.

The HPA Family Guide to Hospice Care describes the services that all hospices are supposed to provide and the problems that may arise within hospice. Yet, some patients and families are confronted with much worse than simple violations of standards of care;

some patients and families are confronted by a healthcare system and staff that actively seek to impose death through a variety of methods. These threats to life itself are described in detail in the *Stealth Euthanasia: Healthcare Tyranny in America* book (available online at [www.hospicepatients.org/this-thing-called-hospice.html](http://www.hospicepatients.org/this-thing-called-hospice.html)).

I would like to especially thank HPA board member Vickie Travis for her dedication and assistance for the many years she has been involved in advocating for the patients and families who are so very much in need. She reported that her own father's life was taken in a hospice setting which became the turning point when she knew that something had to be done.

Vickie is an example of what every family member and individual should do if they are concerned about the quality of care and treatment of the most vulnerable of patients in our society. Get involved, speak out and do something. The quality of care and overall treatment of patients will only improve when each of us, when you, become involved.

## **About the Author**

Ron Panzer is the founder and President of Hospice Patients Alliance. He has spent decades serving the public as a nurse in several settings, and has worked with hospice patients in severe crises in their own home and in hospice facilities, as well as in nursing homes. After working for a large hospice, he resigned when the hospice administration's Board of Directors decided to *intentionally* violate the standards of care for hospice in order to boost its own financial standing. Even when directly confronted by the author and several other nurses, and reminded that the hospice's purpose is to serve the patients' needs, the hospice insisted on continuing to violate the standards of care without regard to the patients' welfare.

Many patients and families suffered severely due to the decision of the hospice. After researching this hospice and others, a pattern of intentional abuse and exploitation of the patients for the hospice administrative personnel's own financial well-being emerged. Extremely well-paid administrators enjoyed extravagant perks and benefits while services to the patients were being drastically cut. The author learned that similar practices were and are occurring in many areas of health care in the U.S. and that the U.S. government is

seriously concerned with stopping these types of practices by hospices. In order to help prevent similar problems from affecting other hospice patients and their families, Ron formed the Hospice Patients Alliance as a nonprofit organization dedicated to promoting quality hospice care, what he calls "the heart of hospice care."

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## Introduction

### Welcome to *The Hospice Patients Alliance Family Guide to Hospice Care (What Most Hospices Won't Tell You)*.

This book is a consumer guide to hospice care written for those who are experiencing the serious challenges which arise out of the impending death of a loved one. Hospice Patients Alliance, Inc. is a nonprofit, charitable, patient advocacy organization serving the general public.

Hospice Patients Alliance promotes excellence in care for the terminally ill, their families, and care givers ... quality hospice services. By providing an extensive resource of information about hospice, death and dying and by helping to resolve problems in the hospice industry, the Hospice Patients Alliance serves to protect the terminally ill, their families and care givers from being under-served or poorly served by hospice agencies.

Services provided by HPA to the public include:

- -free full disclosure of information about hospice regulations, standards of care and how to obtain the very best hospice care, through the Hospice Patients Alliance website at: [www.hospicepatients.org](http://www.hospicepatients.org)
- -free consultations about specific patient/family situations involving hospice care or access to hospice care, via online e-mail or via telephone.
- -free assistance in resolving problems encountered in hospice care,
- -and, this book, *The Hospice Patients Alliance Family Guide to Hospice Care*, along with other books, *Stealth Euthanasia: Healthcare Tyranny in America* as well as *Restoring the Culture of Life (The Ethics of Life In Healthcare and Society)*. This book is subtitled "What Most Hospices Won't Tell You," because most hospices will not tell you up front what is contained in our book. If they told

you all the things that might go wrong, you might think twice about using that hospice's services. Most hospices will not provide details about the problems that you may encounter, or the services the hospice might not provide, even though required to do so by the standards of care. Many hospices will not tell you about past problematic experiences with your loved one's attending physician, or past problematic experiences with certain treatment plans or medications which your attending physician may order or not order.

If the hospice is one of the "rogue" hospices which do not follow the standards of care, they will certainly not tell you, and will not provide you with full informed consent about the services you are entitled to receive as part of the "hospice benefit." They will not tell you what you absolutely need to know to keep your loved one safe and to make sure he or she gets the best possible care.

## **Health Care Fraud & Exploitation**

Unfortunately, health care fraud exists in every field of health care, even hospice. Whether it is insurance companies, hospitals, nursing homes, doctors or hospices, patients and families become victims of a system which protects the businesses conducting the fraud and leaves the patients and families to be exploited. State governments working to reduce their budget may reduce the funding for state inspectors who certify and license the hospices in that state. With fewer state inspectors, hospices may "get away with" violating certain standards of care, because there aren't enough inspectors to properly keep track of all the hospices. Also, some state inspectors may "wink" at severe violations if they become friends with the hospice administrators and sit down and drink coffee and otherwise befriend the administrators of the hospitals, hospices, or other facilities they inspect.

State inspectors are hired and managed by state administrative department directors who are appointed by the Governor of your state. Political and business connections do influence how the state administrative agencies enforce the standards of care in health care. An administrative director for the state licensing and certification department may have a philosophy of not enforcing the standards of care, selectively enforcing the standards of care with some hospices but not others, under-enforcing the standards of care, or simply, "enforcing" the standards without imposing harsh penalties on serious violators of the standards.

Sometimes this means finding that a particular hospice violated the regulations, but not doing anything significant to effectively change the hospice's practices ... for example, letting the hospice get off with a "slap on the wrist" by citing a violation and simply letting the hospice state on paper that it "plans" to correct the problem. The state assumes that a hospice that "plans" to correct a problem will actually do so. The reality is that hospices (and other health care agencies) may simply put in a "plan of correction" on paper, and then not correct anything, or simply create paper documents that make it appear that something significant has been done to correct the problem. That is the most important reason that the state bureaucracy fails to protect the patients and families served by the health care industry in your state.

It is no longer realistic to simply trust that everyone who cares for you or your loved one will always do the very best for you. If you belong to a Health Maintenance Organization (HMO), you may not even be informed of treatments which could save your life or cure an illness, because the HMO wants to save money! Insurance companies routinely deny claims for services that they are obligated to pay for, but they continue to deny such claims knowing that some people will not challenge them and will simply pay the bill. This policy of denying claims that are valid is acknowledged by inside insurance claim adjusters who work in the field.

In the 21<sup>st</sup> century, all insurance companies are administered in a way that resembles the HMOs. It's called managed care. With government-administered healthcare, through the so-called "Affordable Care Act," care will be tightly regulated to insure that expensive treatments are discouraged or even outright denied to various populations, especially the elderly, disabled and chronically ill (See the *Stealth Euthanasia* book for details).

When a private insurance company commits fraud, patients or family members can call on government representatives to correct the problem. When the government is the entity administering the healthcare plans, there will be nobody but the government to appeal to. In other words, those denying care will be those who will hear your appeal, and that they will be very unlikely to hear you is certain.

In any case, patients will, and do, need family members, friends or other individuals to advocate for these needs, to help protect them and help them get the care they require.

Insurance fraud committed by some of the private insurance companies is a rampant white-collar crime occurring throughout our nation. In this way, insurance companies take in money from insurance premiums but do not pay for the services covered under the insurance policies. Obviously, more money taken in and less money paid out makes for very large profits for the insurance companies who commit these crimes.

Hospitals and pharmacies sometimes double-bill for equipment, medicine or supplies used. When they double-bill, they send the bill to two different insurance companies, or to one insurance company and the patient who received the service. Often the patient does not know or understand that the insurance company is going to pay for the service, so the patient pays it. The insurance company does not know that the patient is going to pay for it ... and the hospital or pharmacy gets paid twice for the same thing! That is health care fraud, and the state and Federal Government are working to prosecute such white-collar crimes.

The U.S. Office of Inspector General ("OIG") and U.S. Attorney's Office (Dept. of Justice) investigate these and many other criminal activities. Unfortunately, the U.S. OIG and U.S. Attorney's office do not have enough staff to investigate all complaints and reported violations in a timely manner. They have reported that they are "swamped" by the number of complaints coming into their offices. Such complaints number in the many thousands and they are made in every state of our nation. According to their agents, it is common for their offices to take three years to complete an investigation and bring charges against the criminals involved in fraud. In addition, there are some who might argue that these government agencies do not have the real "will" to ferret out all of the fraud that is occurring, and that these agencies only catch a very small percentage of the health care fraud that is occurring.

Knowing that fraud occurs, even in the hospice industry, and being informed about your rights can make you an "informed consumer" of hospice services for your loved one. Being informed is the best protection you can have against any form of exploitation which might occur during your contact with a hospice. You won't be fooled or misled by a hospice representative who misleads you by telling you that a particular service is "not available" or "your loved one doesn't fit the criteria for that service," even if he or she does qualify.

## **Dealing with Death and Dying**

When you or your loved one receive a diagnosis of having a "terminal illness," it is like receiving a death sentence. The emotional upheaval felt can be overwhelming, and the physical challenges ahead may be more than one person can handle alone. Most of us need a lot of help at this time. We may not even know where to turn for help. Our

physician may refer us to a hospice for assistance. A hospice agency can help with all aspects of dealing with death and dying. Hospice agencies are required by the standards of care to provide all the nursing assistance, home health aides, social workers, counselors, medications and equipment ... needed to meet the challenges of a terminal illness.

Death is experienced in every family. Everyone is touched by the issues of death and dying, caring for the terminally ill and the need for help in that effort. Whether it is a close family member, a friend or co-worker, death eventually makes its presence known, even though we hope it never does. Our society has tended in the recent past, to put death and illness behind closed doors at the hospital or home. Death and dying are "hush-hush" matters which most people do not freely discuss or feel comfortable discussing. The hospice movement has begun to change that. Hospices have a great impact on how our society views death and the process of dying. The hospice movement has begun to open up the communication process about death and dying. It is no longer a taboo subject to be discussed in private. Hospice (referred to in general here) is not a place, an agency, a facility or hospital.

## **What Hospice Is**

Hospice is a way of caring for the terminally ill that respects and honors the person, focusing on promoting the terminally ill person's comfort, assuring relief from distressing symptoms, and supporting that person and his or her family throughout the difficulties and challenges of death and dying and the grieving process both before and after death. In hospice care, the patient's physician writes the medical orders for appropriate care, and then the hospice team of professionals is expected to arrange for needed care and treatments.

The hospice team is central to hospice care and is composed of the hospice medical director, the RN case manager, the social worker, therapists, home health aides, home service aides, other nurses, spiritual counselors, and other hospice staff. The hospice staff works closely with the patient's attending physician to create a plan of care that meets the needs of the patient and the family.

There are thousands of different hospice agencies providing hospice care throughout the United States. In most major cities, there are several hospices serving the public, however, most people are not aware that there are many hospices. When hospice representatives speak about hospice, they simply refer to "hospice" as if it was one nationwide healthcare provider or one "thing."

The people in the community usually have no idea that there are so many hospice agencies competing with each other, just like hospitals, home health agencies, nursing homes and clinics. In any one state, there may be hundreds of different hospice agencies! Yet they are all supposed to promote the well-being and comfort of the terminally ill, their families and care givers.

In some states, the number of hospices in each county or region is limited by the state department of health. Each hospice in these states is required to *certify* that they are meeting the public need for hospice services. For this reason, those states that limit the number of hospices, hospitals or other agencies in any one area are called "certificate of need" states. In such states, there might be only one or two hospice provider agencies in the area who basically have a state-approved monopoly.

When a patient enrolls in a hospice program, he or she expects to receive care aimed at relieving pain and distressing symptoms and at helping all get through this difficult time. Most people place deep trust in the nurse or physician who cares for them. This is especially true when patients and families get involved with a hospice. Some patients and families feel stunned, shocked and betrayed if they do not receive that quality care from their hospice agency and its staff.

## **Hospice Scandal Kept Secret**

*It is one of our country's best-kept secrets that some hospice agencies do not assure the very best care for the terminally ill!* The local media (newspapers, radio and TV stations) do not want this scandal to be exposed. Quite often hospice Boards of Directors include prominent members of the local business and social community, as hospice is something everyone is now trying to promote. Although local media have refused to cover stories about fraud committed by their own local hospices, the national newspapers and TV have occasionally touched the subject. When a national newspaper, The Washington Post, ran a story [\(1\)](#) about exploitation in hospice agencies, the hospices and the national lobbying

groups protested loudly and denied that there was a serious problem in their own industry. What else would one expect from the industry being exposed?

However, smaller community media leaders fear exposing the corruption in a local hospice, because they work closely together with the local hospices promoting hospice and its worthy goals. Many media outlets have refused to cover this scandal even when presented with overwhelming proof, complaints from families, and official reports from state inspectors! We can easily confirm the seriousness of the problem when we consider the well-documented efforts made by the U.S. Office of Inspector General to combat hospice fraud.

Some hospice agencies cut corners and services without informing their patients. Quite often the patients and families have no idea what services they are entitled to receive under the laws governing hospice care. Many patients and families do not even know that there are uniform standards of care throughout the industry which are established in the United States Code of Federal Regulations. These federal standards are established by laws enacted by the United States Congress.

The great tragedy occurring is that some hospice agencies routinely exploit some of their patients for financial gain. This occurs when they do not provide the services the patient is entitled to receive. Because hospice agencies are paid on a "per-diem" basis, they receive a set amount of money for each day the patient is enrolled whether all services are provided or not. The hospice agency is expected to provide all services needed by the patient and the family, but this assumption is not always accurate.

Our newspapers are filled with stories of corrupt white-collar criminals who have penetrated into the administration of various health care agencies, stealing millions of dollars from the federal government, state government or private insurance companies. Double-billing for services is one example of health care fraud. Billing for services not rendered at all is another. In hospice, a hospice agency can choose to simply not provide all the services required to be provided, and the hospice agency will reap financial rewards.

Double-billing for services, bribery and kickbacks have been well-documented in the hospice industry. Administrators who set up these questionable and criminal practices, also arrange for their Boards of Directors to pay themselves obscenely extravagant salaries and benefit packages. CEOs of some large nonprofit hospice agencies receive over \$400,000 per year, yet the public makes donations to the nonprofit hospice agency so that care is provided *to the patient. Those donations go into the pockets of those CEOs!*

## **Many Hospice Professionals Extremely Dedicated**

While some hospice administrators may take advantage of their position for their own personal gain, many do not. Many hospice staff are extremely dedicated and caring. It takes a very special type of person to work with the dying and their grieving families. Although death is not easy to confront, there is a great opportunity for the expression of love, compassion and understanding.

There is a difference between dying and death. How we or others die is part of how we lived up to the very last moment of life. The choices we or others make as we die communicates much about how we have lived: what our values are, who and what we care about. What is done or not done speaks volumes about our philosophy of life. Every person has a personal outlook on life ... beliefs about the meaning of life and individually, one's own purpose in living. Death will confront us all sooner or later, but dying does not need to be painful, depressing or even catastrophic.

## **Problems in Hospice Confirmed by U.S. Government Reports**

The U.S. Office of Inspector General has issued lists of improper, illegal and fraudulent hospice practices it found to be occurring around the country. This book has been written in order to help protect hospice patients, their families and care givers from these types of illegal practices. Some of the illegal hospice practices listed in a recent report<sup>(2)</sup> include:

- "uninformed consent to elect the Medicare Hospice Benefit,
- discriminatory admission,
- admitting patients to hospice care who are not terminally ill,
- arrangement with another health care provider who a hospice knows is submitting claims for services already covered by the Medicare Hospice Benefit [double billing]

- under-utilization,
- falsified medical records or plans of care,
- untimely and/or forged physician certifications on plans of care,
- inadequate or incomplete services rendered by the [Hospice] Interdisciplinary Group,
- insufficient oversight of patients receiving more than six consecutive months of hospice care,
- hospice incentives to actual or potential referral sources (e.g., physicians, nursing homes, hospitals, patients, etc.) that may violate the anti-kickback statute or other similar Federal or State statute or regulation, including improper arrangements with nursing homes,
- overlap in the services that a nursing home provides, which results in insufficient care provided by a hospice to a nursing home resident,
- improper relinquishment of core services and professional management responsibilities to nursing homes, volunteers, and privately-paid professionals,
- providing hospice services in a nursing home before a written agreement has been finalized, if required,
- billing for a higher level of services than was necessary,
- knowing billing for inadequate or substandard care [emphasis added].
- inadequate justification in the medical record when a patient revokes the Medicare Hospice Benefit,
- billing for hospice care provided by unqualified or unlicensed clinical personnel,
- false dating of amendments to medical records,
- high-pressure marketing of hospice care to ineligible beneficiaries,
- improper patient solicitation activities, such as "patient charting,"
- inadequate management and oversight of subcontracted services, which results in improper billing,
- sales commissions based upon length of stay in hospice,
- deficient coordination of volunteers,
- improper indication of the location where hospice services were delivered,
- failure to comply with applicable requirements for verbal orders for hospice services,
- non-response to late hospice referrals by physicians,
- knowing misuse of provider certification numbers, which results in improper billing,
- failure to adhere to hospice licensing requirements and Medicare conditions of participation [failure to provide proper care according to the standards of care],
- knowing failure to return overpayments made by Federal health care program."

[emphasis or comments added by the author of this book appear in brackets]

While some of these violations may appear technical or confusing to those who are not familiar with the laws governing hospice and the health care industry, it is obvious that

some hospices are knowingly committing Medicare fraud, violating patient and family rights and providing substandard care to many.

## **How to Use This Book**

While you may wish to start and read this book cover-to-cover, you can also pick topics of interest to you which address your specific needs. If you are not fully familiar with the services available in hospice, we encourage you to read the entire text.

This book is organized according to groups of subjects which explain the needs of the terminally ill, the care provided by hospices, and the laws governing hospice care. It is very important to understand that hospices must provide the services which are mandated by the federal laws governing hospice (the United States Code of Federal Regulations, Title 42, part 418). Hospices are not free to pick and choose which services they offer you. This means that in hospice, you and your loved one have specific legal rights to health care services from the hospice you choose.

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## **HOSPICE PATIENTS ALLIANCE MISSION STATEMENT**

The Hospice Patients Alliance (HPA) is a private nonprofit charitable corporation dedicated to serving the general public, hospice patients, their families/care givers, the bereaved and hospice staff. HPA promotes quality hospice services whether a patient is enrolled in a licensed hospice or not, whether residing at home or in a facility.

HPA protects the rights of patients, their families and care givers, the bereaved and staff by providing information about the standards of care governing the health care provided, the services required to be provided by law, standard industry practices and how to obtain the very best hospice care available.

HPA was initially formed as a positive response to serious violations of patient and family rights by hospice agencies. HPA has a nationwide focus and serves wherever there is a need. HPA is not controlled by any hospice agency, institution or lobbying group!

Almost all web sites related to hospice are controlled by hospice agencies themselves or their lobbying groups, and they do not mention the glaring problems in the hospice industry. While they provide very general information about hospice, they often do not offer direct and effective assistance in solving the problems in hospice.

HPA is an independent organization governed by a Board of Directors comprised of health care professionals and families of patients who had terminal illnesses. We are solely dedicated to you: the people served by hospice. For the very best information regarding hospice care, you can browse our website on the Internet, contact us directly, and use our web-links to access related important web-sites!

To obtain answers to your individual questions about hospice services, please e-mail us or call us. The Hospice Patients Alliance is supported totally by donations from the general public. Your support is vital to our mission.

We hope that this book and our website will be helpful to you and those you love! Your support and feedback are greatly appreciated!

## **A LETTER FROM HOSPICE PATIENTS ALLIANCE**

This book, along with our website, is being provided as a service to all of you who are seeking to learn more about hospice and how to most effectively meet the needs of your loved one, family and yourselves. Hospice Patients Alliance serves you in the spirit of "consumer advocacy" and protection of your rights. We educate the general public about hospice and how to obtain the very best hospice care services available.

The health care industry can sometimes seem like a stormy sea of confusing medical jargon and technical information which is not easily navigated. In addition, some health care agencies (and hospice agencies) have strayed from the "charitable" mission we normally associate with compassionate, loving care. The increased profits for stockholders and top executive salaries has become the goal for some, rather than the assurance of quality services for the patients and their families. We hope to explain the world of hospice to you and assist you in your situation.

All of us are touched by hospice in one way or another: a friend, relative or other acquaintance. We hear stories of the type and quality of care provided by hospices all the time. More and more Americans use hospice services for family members or themselves, and the percentage is only going to increase. Why?? Because knowledgeable hospice care is cost-effective and prevents many emergency visits to hospitals during a terminal illness. Hospice programs also save money for the federal and state government-funded Medicare, Medicaid and overall healthcare programs as well as saving money for private insurance plans.

Today's health care agencies use the rationale of "making the organization more efficient" as an excuse for cutting services, staff and quality ... all the time maintaining that "quality of services has not been affected." We live in an age of double-speak and outright deception by public relations experts who market the agency and spin information without regard to the actual facts involved in the patient care settings. To many patients' dismay, the "baby is being thrown out with the bath water," and services have been cut unconscionably. The agencies will never admit these facts to the public.

Some agencies resort to health care fraud and deprive many individuals of services that they are entitled to receive ... and they continue to bill the government for services never provided. Do not let this happen to you! Learn as much as you can and demand the very best services. You are entitled to it. Some of the largest and "most professional-looking" hospices do under-serve their patients or may even be involved in different forms of health care fraud. You have paid into the system and now is the time to get what you deserve: for it is through your tax dollars and/or insurance premiums that a large part of the hospice services are funded.

Today's health care industry is made up of a vast number of businesses which exhibit some of the most admirable and most detestable characteristics of mankind: on the one hand we see staff with great dedication to serve the patients, ever expanding knowledge of health care, disease and treatments along with new capabilities and technology. On the other hand we see business administrators with no conscience violating the rights of the patients served. In contrast with the "rogue" administrators who do not care, there are

many administrators struggling to provide the very best and still meet the challenges of competing in today's cutthroat market.

There are many administrators whose only concern is expanding a business which happens to be health care and making as much money for themselves as they can (as long as they're in power). Some unethical administrators are getting rich from skimming the money coming into their agencies (paying themselves a huge salary, as well as benefits and other perks). The rise of huge health care agencies that bully other agencies out of business, or acquire numerous health care agencies and create health care "empires" is a disturbing trend. The modern world of business can sometimes be as vicious as a shark-infested ocean, and let the recipient of health care beware: you *are* being affected by these developments in health care! When large monopolies are created in health care, your freedom of choice is severely limited.

If you are about to enroll in a hospice program or at least thinking about it, you have probably been through much of the "curative-treatment" side of the health care system and may have experienced some problems in your care (hopefully not). Doctors, nurses and other staff who work for health care agencies routinely "see things done" which ought not to be done, and when they protest to management, they often either get feeble excuses or the runaround. If they protest too vigorously, they get terminated and made an example of for any other staff that might dare to speak up for the patients, families and the standards of care.

There is a real war of values going on right now in the health care industry and many brave health care professionals have risked much to fight on behalf of the patients and the standards of care. On the other hand, too many staff are too afraid to say anything at all, fearing the loss of their jobs and the financial well-being of their families. Many openly complain that "there is nothing that they can do." Fear of personal risk is common among health care professionals. We at Hospice Patients Alliance believe that there is something we can do: be informed, work together for the betterment of all, and stop the exploitation of patients, families and staff.

There are many physicians, other health care professionals and their associations who are severely concerned about the changes taking place in the industry, changes which violate the very heart of health care and compassion. These changes are being made by individuals (at health care agencies) who care less about compassion and quality care than amassing personal fortunes and creating dividends for stockholders (in for-profit corporations).

While it is necessary to make a profit or take in enough to pay for services provided, it is completely inexcusable for top-level administrators to get rich by stepping on the rights

of the patients and staff, in order to get there. There are many administrators with integrity, and we salute them. But those administrators who exploit patients, families or staff and knowingly violate the laws governing health care need to be stopped and the justice system needs to prevent them from continuing to do what they have been doing without regard to those who are supposed to be served by their agencies.

While those working within health care are well aware of these problems, the media outlets rarely lay bare the full details of what is going on in the hospitals, nursing homes and hospices -- especially if it has anything to do with a local agency. Health care agencies often share members of their Board of Directors with members of the media or their Boards of Directors. One hand washes the other, so to speak, and the media protects the local agencies from full disclosure. It is not easily possible to learn about the mistakes, violations and exploitations committed by your local health care agencies!

Those who have tried to publicize the disturbing trends in health care know that there is an absolutely real "wall of silence" regarding this problem especially on the local level. It is "ok" for local news organizations to report about abuses elsewhere, but newspapers, TV and radio stations will not publish or inform you about daily violations of patients' rights going on right under your nose. Local media often refuse to publicize problems at local agencies, even when furnished with proof of severe violations. If you wish to find out what is really going on, you have got to be on the inside or know someone on the inside!

We have provided within this book (and our website) valuable inside information on hospice care and the industry in general to help you navigate the troubled waters of modern day hospice care. This information comes from hundreds of hospice professionals who have added their observations and insights to what we report.

Not all hospices are involved in the violations of patients' rights and health care fraud. There are many dedicated staff working in many hospices, and we encourage you to contact one of the local hospices in your area. We know that you may be going through one of the most difficult times in your lives and hope you will contact us if you need any assistance.

Sincerely,

Ron Panzer, Pres.  
Hospice Patients Alliance, Inc.

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## CHOOSING HOSPICE: IS IT RIGHT FOR YOU?

If you are even contemplating hospice care, you or your loved one must have been diagnosed by a physician with a "terminal illness." What a shock and heartache! No one is truly prepared for such a pronouncement ... and to be "certified" as "eligible" for hospice care the doctor must state that according to the statistics the illness may cause death within six months or less. [\(3\)](#)

That may be so, but some patients live much longer than that, some for years. However, many do pass on within six months or less. It is not really possible for a physician to predict, with absolute certainty, how much time is left. Whatever time is left is so precious that hopefully it will be lived as fully as possible. That is where good hospice care comes in. Quality hospice care can make the difference between overwhelming stress, symptoms which may be unbearable, and living peacefully and meaningfully up to the very end. Hospice is about living to the fullest while time is left, maintaining your dignity, and most of all about caring for one another.

Choosing to use hospice services is an affirmation of the meaning of your life, not giving up. It allows you to optimize the time you have, control symptoms, and do what you need to do. For the families and care givers, hospice provides the support and training to deal with the crisis that is often part of approaching death. Dealing with symptoms related to the terminal illness is a specialty with unique applications of medications and ways of administering medications that provide for the patient's comfort and well-being. Many physicians and nurses who are not experienced in hospice care do not know how to deal with these symptoms. Even in the hospital you are not guaranteed the best care for such terminal illnesses!

Specialists in other areas of medicine are not trained in the latest and most effective manner of managing distressing symptoms which arise as a result of terminal illness. The central focus of hospice is to support the patient and family throughout the course of the illness, and the family/loved ones for a minimum of one year after the patient's death, in a wholistic approach and to manage symptoms (palliative care). Hospice does not attempt to cure or treat the terminal disease itself, but rather serves to promote the comfort and peace of the patient and family.

Choosing hospice means choosing to optimize quality of life, but it also takes an honest realization that we are no longer trying to cure the disease, but are working to minimize the symptoms of the disease and keep your loved one comfortable. This is often the stumbling block which keeps patients and families from accessing hospice care sooner.

For some, using hospice is "admitting defeat." Some physicians hesitate to refer patients to hospice until the very end, which is really tragic. There is a difficult transition to be made by some physicians from the "curative" care mode (where they are still trying to find the "cure") to the "hospice/palliative" care mode, when the realization is made that at this point no treatment is available which will have any reasonable chance of success.

For these reasons (resistance on the part of patients, families and doctors to "giving up") many hospice patients do not receive hospice care until quite late in the course of their illness: some as late as two weeks or less before they pass on. While hospice certainly does help even at this late point, research shows that patients who enter good hospice care earlier on in their illness actually benefit more and live longer!

Hospice staff and knowledgeable physicians can prevent some of the distressing symptoms which interfere with proper hydration and nutrition. For this reason, many hospice patients live longer. Nausea and vomiting, for example, can indirectly hasten death through malnutrition and dehydration, while controlling these symptoms can extend life expectancy.

Hospice counselors can assist the patient and the family to complete their "unfinished business." Whether social workers, psychologists or chaplains, hospice staff specialize in dealing with the fears and anxieties that accompany approaching death. You choose which sort of counseling you wish to accept. You always have the right to accept or refuse certain treatment plans, medications or counseling. You (the patient and family as a unit) should have control of your plan of care.

Choosing hospice is a positive step toward making the last days the most meaningful and comfortable for all. It means accessing the help you need, in a way which you govern, for your benefit. You may question which particular hospice in your area to use. Look in your local yellow pages and contact each of the listed hospices; speak with the representatives, learn how they differ, what services are offered, whether the patient can stay home with family to die or whether the hospice will only provide care in their facility. A full-service hospice will help you to stay home if that is your wish. The largest hospice is not always the best hospice. The large nonprofit hospice is not always the best, but many for-profit large hospice chains have been found to be violating the standards of care. Try to find the hospice agency that reflects your values and respects life!

Speak with others you know who have recently used hospice services and ask them what they think of that hospice's services. A recent personal experience with a hospice is perhaps the best indicator of the type of care provided.

So is hospice right for you? The answer depends on what you and your family want. Hospice offers many, many benefits, and hospice care is definitely a major improvement over being in the seemingly "sterile" environment of the acute care hospital to die. For most patients, hospice can help them to stay at home up to the very end. Good hospice care is a blessing to those patients and families in need.

For some there may be some disadvantages to enrolling in a hospice program of care, and the drawbacks really depend on the type of home environment you wish to maintain at this time or on whether or not the patient wishes to enter a facility. Some patients and families have difficulty in having different health care workers in the home and do not wish to give up the privacy of their home. Others feel coerced into placing their loved one in the hospice's facility even though the patient wishes to die at home.

Really good hospice staff will try to be as un-intrusive in the home as possible and respect wishes for privacy, but nevertheless they are physically present. Is it worth it? Most hospice patients and families would probably answer "yes," especially when symptoms are severe and hospice expertise is needed to manage the symptoms and keep the patient comfortable.

As far as facility placement is concerned, if the hospice does not attempt to manage extreme symptoms at home when the patient wishes to stay home to die then the hospice is violating the standards of care which require "Continuous Nursing Care" under the criteria of care.

You must weigh the pros and cons for your situation and do what is right for you! Being informed of the standards of care and what services you are entitled to will go far in assuring that your hospice experience is the very best for all concerned.<sup>(4)</sup>

## **CARE AND SUPPORT AVAILABLE IF YOU NEED IT**

Hospice care is a special kind of health care devoted to respecting the wishes of the patient, family/care givers or the bereaved. Hospice is based on a wholistic approach that provides a wide range of services and focuses on the patient's and the family's needs as well. Hospice care approaches the patient as a person, not "just a patient." What you need and want is central to quality hospice care.

"Good" hospice care is not a forced approach where health care workers tell you what choices you have to make; hospice is about respecting the person, the family and working with you to help you achieve your goals. What your goals are depends upon you, your values, beliefs and individual situation! The hospice staff and your physician must inform you of all options available, all services which may be provided and work with you to create a plan of care that meets your needs.<sup>(5)</sup>

Hospice philosophy involves respecting the wishes of the patient and the family/caregiver unit. You might be surprised to learn that what patients and families want may vary widely from one situation to another. While some patients want pain totally eliminated, others do not want any medication. Some patients wish to remain as alert as possible, while others ask to be sedated. Strong pain medications (narcotic analgesics) may have a sedating effect especially when first started. While it may be possible to be completely alert and relatively pain free, *this is not always possible in all cases*. Different medications may be given for symptom relief, and often, different methods of giving the medications may be used as the patient's condition changes.

Hospice services are to be tailored to meet your needs within the confines of the rules governing hospice care. The benefits of hospice include the staff, medications and equipment needed to meet the needs you have in treating the terminal illness, and the hospice you use must make its services available to you on a 24-hour basis.<sup>(6)</sup> A hospice-trained RN serves as your case manager; the overall plan of care is coordinated by an Interdisciplinary Team who take a wholistic approach to the services to be provided.

The Interdisciplinary Team is comprised of your attending physician, the medical director of the hospice, the registered nurse, a social worker, chaplain, and other health care professionals. In addition to visits by these hospice staff, LPNs and home health aides may visit as needed to assist you at home. If any of you need or want counseling, it must be made available to you. If you choose not to have counseling, you can refuse the service. Counseling services may comprise many different types of services including assistance with solving financial problems, understanding advanced directives and the issues involved, and support in coping with grief.

Hospice care is available on a twenty-four hour basis. If an emergency or question arises, a registered nurse is on-call to answer questions, come to your home to assess the patient and contact the physician for orders, if necessary. In addition, if symptoms do become uncontrolled, nurses will be sent out to stay with the patient and family, in your own home, to get symptoms under control.

The attending physician (your doctor) must approve or "write the orders" for all services, support, and equipment you may need. For this reason it is extremely important that your

physician be knowledgeable about caring for the terminally ill and that he or she agree with the standards of care for hospice. This means that the physician subscribes to the accepted standard methods for controlling symptoms which may arise in the course of a terminal illness.

Not all physicians are aware of the standards of care and not all physicians subscribe to the standards in the hospice industry! By choosing to use hospice services you are much more likely to receive care that is the most up-to-date and effective in controlling symptoms and in supporting you through these difficult times.

If your symptoms are well-controlled there is no problem. However, if pain increases and is not controlled you need to communicate clearly with your physician and RN case manager to make sure the patient is kept as comfortable as possible. For example, there are many different medications used and different methods of treating pain of varying types. By changing dosages of medications for pain, by changing the route of administering the medications, or by giving the medication more frequently, a patient can be kept comfortable. (See "Standing Orders," "Pain Control," and "Narcotic Medications." The key is to communicate clearly to the hospice staff so that your comfort can be maintained. If the hospice staff do not ensure the patient's comfort, clear communication with the nursing director or physician is necessary.

If at any time your attending physician refuses to give the orders needed for your care and comfort, then you have the right to speak with and consult with the hospice's medical director. He or she must intervene, by law, to assure that your needs are properly met. So by choosing hospice you are helping to assure the very best patient services for the patient and family.

You always have the right to choose which doctor in your community serves as your attending physician. You may have been assigned a physician at the hospital after learning of the terminal illness. This does not mean that you have to continue to use the services of that doctor. Although it is not commonly necessary, you do have the right to change doctors if you choose to do so. If you cannot find a physician to help, you may try contacting one of the patient advocacy, elder rights groups, or right-to-life organizations in your state or area and ask for a referral.

If you are not receiving adequate pain control or the medications are too sedating and you do not want to be sedated, you need to discuss your wishes with your physician. Be assertive if you are not getting what you need! If you still experience difficulty, please call us at Hospice Patients Alliance.

## CHOOSING THE RIGHT HOSPICE IN YOUR AREA

Which hospice you choose is only an issue if there is more than one hospice agency in your community. Most people assume that there is only one hospice, and when others say, "we had hospice also," they believe it's the same hospice. This is not the case! While in remote areas, you may only have one service provider, in many greater metropolitan areas and surrounding counties, you may have many hospices in your area.

The best way to find out how many hospices exist in your area is to look in your local yellow pages under the heading "hospice," "home care," or "nursing." Do not rely only on Internet listings of hospices, because they are most often not complete lists (even if they say they are). Internet directories often list members of a particular hospice organization and then assert that their lists are "complete."

Larger hospices may be better able to pay for frequent newspaper advertisements, but that does not make them better hospices. In addition, because a hospice belongs to a "hospice organization" (whether national or statewide) does not make that hospice superior to other hospices in the area. Some hospices may choose not to join the state or national hospice organization, because they do not wish to pay fees or dues to the organization (feeling that they may not get their money's worth), due to political considerations which have nothing to do with the quality of care, or because the organization is actively trying to promote forms of stealth euthanasia within the hospice industry. (See *Stealth Euthanasia: Healthcare Tyranny in America*).

A better indicator of quality hospice care is to find out if the hospice is accredited by an organization such as the Joint Commission on Accreditation of Healthcare Organizations ("JCAHO" for short). If a hospice is accredited by JCAHO, it agrees to inspections by JCAHO and must meet higher standards of care than those hospices which are not "JCAHO accredited."

Many small hospices provide excellent care. Ask your physician for the names of recommended hospices in the area or contact a social worker (discharge planner) at one of the nearby hospitals and very specifically ask for the names of all hospices serving your area.

Do not simply assume that your physician or the hospital social worker will automatically give you all possibilities. If you do get a referral to one particular hospice, ask for reasons why the hospice is better than the others in your area. Openly discuss your needs with

your physician, because your attending physician may ultimately choose to be in charge of your care and all the services you receive. You do not have to relinquish your attending physician when you enter hospice!

If your physician refers you to one hospice, he or she will most likely have very good reasons for choosing that hospice. However, it may simply be that that hospice is chosen because it is part of the same health care "system." If your physician is a specialist who regularly works with terminal patients, he or she normally will recommend a hospice for its superior services.

Which hospice you choose is one of the most important decisions you will be making. If you know anyone who has utilized a hospice in your area find out what their experience was like. A good reference from someone you know, who shares your beliefs and values, and who you trust, who recently used a hospice, is one of the most reliable sources of information. However even these references may be "subjective" evaluations, and your situation may be different from theirs.

Much information can be gathered by visiting different hospice facilities; speaking with the staff; finding out how many patients each nurse takes care of on a shift (are they adequately staffed?); observing how clean the facilities are, and speaking with the families of patients at the facilities. Even if you plan on staying at home, a brief visit to a hospice's facilities will give you a "feel" for how the hospice operates.

If it is early in the course of the illness and you want extensive information about a particular hospice, you could call your state's Department of Health Services (each state has varying names for these ... such as Dept. of Public Health or Bureau of Health Services) and ask for the phone number and address of the state's "Freedom of Information Office." By law each state's administrative division inspects, licenses and certifies the hospices to assure they meet the legal standards of care governed by law in federal and state regulations for hospices. When an inspection is performed, a "survey summary" is completed and must be made available to the public. Write to the state offices and specify that you are making a request under the Freedom of Information Act and wish to receive a copy of the survey summaries for the most recent inspections of a particular hospice in your area. Also request a copy of any inspections performed as a result of any complaints filed with the Department. These survey summaries provide detailed information that will give you an idea about what problems might be occurring in a local hospice. [\(7\)](#) These surveys contain information that the hospice will definitely not voluntarily reveal to you!

If a complaint had been filed, the state surveyor will look through the medical record or "chart" to see if there is evidence that the complaint "allegation" or "charge" is verifiable.

If there is evidence that a violation occurred the surveyor will state that there is a "basis" for the complaint and "cite" the agency in violation of a particular standard. The hospice will then have to file a plan of correction to remedy the violation which occurred. If the surveyor writes that a complaint is "unsubstantiated," it does not mean that the violation did not occur! It simply means that the chart does not show whether it occurred or not ... there is not enough evidence in the chart, and the chart is the "legal record" of the care that was or was not given. Choosing a hospice is an important step in keeping your loved one comfortable. Being informed about the care and services to which you are entitled, and clearly communicating your wishes will help you obtain the very best care.

## **CHOOSING TO STAY AT HOME: MAKING IT HAPPEN**

If the patient wishes to stay at home up till the very end, you need to make that wish clearly known to your RN case manager, the social worker, your physician and any other hospice staff. If there are other family members available to help out, discuss this decision with each other and make sure that all family members are working together toward your goal. You should make sure to request hospice volunteer services to help out.

In some cases you should be prepared for hospice staff who might attempt to convince you to bring your loved one to the hospice facility. This may be appropriate for some patients. You, as patient or family/caregiver, have rights to choose to stay home. Nobody can force you to enter a facility against your will. However, if you do choose to stay home, you need to mobilize all resources and assistance you can muster to help make it happen. Whether you have the immediate family, relatives or close friends care for the patient, you will probably need many types of assistance. If the family and friends can volunteer to work together, that is the ideal situation.

The hospice must meet the needs of the patient and family unit. <sup>(8)</sup> Services which are required to be provided include family needs for support and counseling. If symptoms become out of control and the patient experiences uncontrolled severe pain or other symptoms then the hospice must provide, in most circumstances, what is called "Continuous Nursing Care" in your own home (around the clock nursing at home, from 8

to 24 hours of the day, provided by licensed nurses more than 50% of the time, with the rest of the care provided by home health aides).<sup>(9)</sup>

A registered nurse (not an LPN) must personally visit the patient to assess his or her condition each day continuous care is being provided. If the patient's symptoms are brought under control then continuous care may be discontinued. However, if symptoms remain out of control, the RN may continue to have nursing staff provided around the clock in your home. Each day, the hospice will re-evaluate whether Continuous Nursing Care in the home can be continued. Continuous Nursing Care may also be provided when the patient is near death.

The hospice will help you learn how to care for the patient at home. Hospice staff normally will not be there all the time! The registered nurse will teach you about the medications to be given and how to give them. If you have questions after hours you can always call the hospice's on-call nurse. Whatever the situation, the hospice staff are experts in handling the types of situations that arise. There is much information available that can help you keep your loved one at home. Read whatever literature the hospice provides and ask questions. Discuss your wishes among yourselves as a family and with the hospice staff. The more you communicate, the better the outcome will be.

## **DEALING WITH APPROACHING DEATH**

Receiving a diagnosis that includes a probable life expectancy of "less than six months" is one of the worst moments imaginable. No special "words of comfort" or philosophical discussion is going to make it better. However, we can make the most of the time that is left and make the "quality of life" the best possible. The will to live is one of our strongest instincts. Hospice offers a positive approach to coping with all the changes that accompany the dying process.

There are many factors that affect how such a diagnosis is received: the age of the patient, the "world view" of the patient and family, beliefs in God and an after-life or a belief that there is no "after-life," the nature of the disease and its cause, etc. Although some might imagine that everyone would agree with the statement "nobody wishes to die," it is not possible to make such an assumption and generalize. Some who have lived a very long and full life may be ready to pass on. Those experiencing terrible pain may

wish to escape it through death, not knowing that in most cases quality hospice care can control the pain and help the patient to be more comfortable.

There is no easy answer to "why" death comes to the very young or old when it does. Each of us must find our own answers, and those answers involve beliefs about the meaning of life, purpose in living, our relationships with those around us, our work, family and friends, and our goals.

Disbelief, shock and anger at hearing such a diagnosis is common, and it may take a long time for the initial shock and anger to subside, if it ever does. Disbelief and denial are natural and understandable responses to such a life-changing diagnosis. Time however, has a way of making the reality of the disease known. Health and energy levels may decline while symptoms worsen, all of which make continued denial impossible. Grief and depression are common.

While to some, acceptance and peace seem to be unattainable far-off goals, others arrive at a state of peace and acceptance that comforts all around and allows for the expression of loving feelings among family and friends. The imminence of death forces us to confront our own mortality, fears and beliefs. It also can help us overcome past hurts and grudges and reaffirm our love for one another. When death is imminent, we are also forced to make many decisions about the care given, interventions made, when to let go and what type of funeral arrangements will be made. All should be discussed with the patient to make sure his or her wishes are respected.

Hospice staff are available to listen and "be there" for the patient and family. Providing medications to control symptoms is only part of the hospice mission. Nurses, social workers and chaplains all work together to help the patient and family arrive at a peaceful resolution of the many complex issues which arise.

## **DIAGNOSING A TERMINAL ILLNESS: IS IT SIX MONTHS OR LESS?**

According to federal laws governing hospice a physician can only certify a patient as "eligible" for hospice benefits (under Medicare) if the patient's life expectancy is six

months or less. This is simply a statistical average life expectancy given a specific diagnosis. It may or may not be true for any one individual patient. While some patients may live much longer than six months, there are others who only live two weeks or so. Each patient's situation must be evaluated on an individual basis.

It is common for hospice staff to hear families' accounts of "predictions" about how long their loved one would live. While some of these predictions are quite accurate, some are not. Debates arise as to whether or not predictions should even be made. The problem is not easily resolved since most of us would ask the physician, "how long will it be?" The physician is placed in the awkward position of predicting that which cannot always be accurately known even though he or she wants to give the patient and family the best hope. However, it is certain that nobody really knows. We encourage you not to rely too much on predictions, and to make the best of the time that is left, however long it may be.

Hospice staff are well aware of some patients who have lived well beyond the six months period. What happens then? Hospice care continues as long as needed to meet the patient's and family's needs. The physician simply "re-certifies" the patient for another period of time, and services continue.

## **HOSPICE FACILITIES**

Many of the larger hospices have their own facilities where care is provided for their patients. These facilities are often located in greater metropolitan areas, and are staffed by specially trained hospice staff that are experienced in caring for the terminally ill. Other hospice agencies may lease beds in a hospital or nursing home as "palliative care" beds. In cases where a family is unable to care for their loved one at home, placement in a facility can assure that the patient receives the care needed. [\(10\)](#)

Some patients feel that remaining at home to die would be too difficult for their family to handle. Others may feel a need for privacy in front of their family. Having care provided in a facility allows the family to remain "family" and not assume the role of "nurse" and "family." Some families have no problem providing the nursing care necessary, while others cannot handle seeing their loved one's decline and pain or suffering.

However, if it is the patient's and the family's strong wish to remain at home to die, then the family must gather all resources available to make efforts to assure that there is someone in the home "around the clock" twenty-four hours each day. If necessary, close friends may be relied upon to help provide care in the home. It is possible for the hospice to provide around the clock nursing care (Continuous Nursing Care) in the patient's own home or even in a nursing home, only if the patient has symptoms which are out of control and need special attention, or if the patient has arrived at the active phase of dying (see the section on Continuous Care Level of Services).

If symptoms are not out of control and the patient is not actively dying, then it is the family's responsibility to provide care when the RN, home health aide and other staff are not making routine visits provided at the "Routine Home Care Level of Care."

When the patient has symptoms which are out of control and resides in a hospice facility, the patient is usually placed on the "In-Patient Level of Care" for which the hospice receives much more reimbursement than when the patient's symptoms are not out of control. (See the section on In-Patient Care Level of Services). If medications are being frequently adjusted, in dosage or changed, or if monitoring of the patient's condition is needed more frequently, then the In-Patient Level of Care may be appropriate. On the other hand, if it appears such interventions should be being made and are not, and the patient is suffering without adequate attention, bring this to the attention of the registered nurse in charge of the hospice facility.

The hospice must provide adequate staff to meet the needs of your loved one and to keep the symptoms under control. If the hospice facility is running "short-staffed" and still has your loved one on "In-Patient Level of Care," then it is possible the hospice is fraudulently billing for a higher level of service which it is not providing! You have a right to know when the level of care changes and to see that increased care is provided when the needs of the patient increase. If you have any questions about what level of care your loved one is receiving, ask the staff at the facility.

In any case, problems which arise due to under-staffing at the facility are certain to adversely affect your loved one's care. If the facility appears to be under-staffed, demand to see the manager and ask what the hospice is going to do to correct the situation. If the problem is not corrected, consider moving to another hospice's facility or filing a complaint with the State and federal government. It is sad that those hospices which exploit the situation of the dying count on the probability that most people will not file a complaint and so they get away with it. Hospices with integrity who do not "play games" with the regulations probably find it difficult to believe that such abuse occurs, but it does.

If there is more than one hospice in your area, check out the different facilities which may be available. Find out how many patients each nurse and nursing assistant take care of. Try to find out if there is adequate staff to meet the needs of the patients. In rural areas when hospices do not have their own facility hospices may arrange for the patient to enter an extended care facility (nursing home) or hospital. The hospice staff will provide care at the facility in addition to the routine care provided by the hospital or extended care facility.

The best time to ask questions about care in a facility is before you enroll in a hospice's program. Because hospice facility staff have the experience and training to manage a wide variety of illnesses and symptoms, placement in a facility may be a good choice for those patients and families who feel reassured by accessing a facility's services.

## **HOW HOSPICE WORKS: THE PHYSICIAN-HOSPICE RELATIONSHIP**

You are probably used to visiting your physician and then getting your medical advice directly from that physician. However, when the attending physician<sup>(11)</sup> refers a patient to a hospice, the hospice assumes responsibility for providing care to the patient based on a Plan of Care which is under the supervision of the attending physician. This means that the patient will not regularly be seen by the physician, but rather by trained hospice staff who work with the physician.

The hospice team (the "Interdisciplinary Team") meets regularly to create and update the Plan of Care. The RN case manager then contacts the physician who either approves or modifies the Plan of Care.<sup>(12)</sup> Although all care is under the supervision or "orders" of the physician, the hospice is basically making most of the decisions regarding how often hospice staff will visit the patient. These decisions are based upon the "assessment" or "evaluation" of the situation by the RN, social workers and other hospice staff, including the hospice's own medical director.

Because the types of symptoms that arise are similar from one patient to another, physicians have learned that standard protocols are effective and appropriate for the treatment of these symptoms. Each hospice works with a team of physicians and creates a list of standard medications which may be used under certain specific situations without

calling the attending physician each time. These medication orders are called "standing orders." Each attending physician who utilizes a hospice's services pre-approves the "standing orders" of the hospice. In the event that the attending physician does not agree to all of the standing orders used by a hospice, then he or she may exclude certain medications and order that these medications cannot be used for his patients without directly contacting him or her for an order. (See "Understanding Standing Orders in Hospice").

An RN (or an LPN who is under the RN's supervision) may start giving routine medications listed on the standing order sheet without calling the physician for a new order each time. The physician is notified that the patient was started on a specific medication "per standing orders" and the physician later officially signs the order for that medication. In this way, the hospice relieves the physician of numerous and frequent calls at all hours of the day and night. These could literally be hundreds of calls in a day if the physician were to be called for every decision!

If there is any question about the efficacy of a standing order medication, or if no standing order fits the patient's situation, the hospice nursing staff will call the physician for specific orders.

Years ago a family could expect the physician to visit the patient at home when the patient was having severe symptoms. Today the hospice staff are with the patient (either at home or in a facility) and the staff act as the "eyes and ears" of the physician, reporting the patient's signs and symptoms to the physician. Nowadays many physicians do not generally make visits to the patient. The hospice staff contact the physician at regular intervals and as needed for updates, and the physician then gives his or her orders for the patient's care. If the hospice's medical director is physically visiting and examining the patient, either at home or in a facility, that is an indication of superior hospice care.

## **HOSPICE SERVICES AND THE INTERDISCIPLINARY TEAM**

Hospice uses a "team approach" to providing health care. The patient and family make up the first part of the Team. The patient and family help to make decisions about the care they need, want, and will (or will not) accept. Because the patient and family are part of the Interdisciplinary Team and are also recipients of the care services, the most important

first step in hospice is to properly inform the patient and family about all services which may be provided. The proper informing of the patient and family is called "Informed Consent" and must be given in writing and explained so that the patient and family understand the scope of services which may be provided.

Sec. 418.62 Condition of participation--Informed consent. A hospice must demonstrate respect for an individual's rights by ensuring that an informed consent form that specifies the type of care and services that may be provided as hospice care during the course of the illness has been obtained for every individual, either from the individual or representative as defined in Sec. 418.3.

Hospice services are provided to you by members of the Hospice Interdisciplinary Team. The Team is made up of Nurses (Registered Nurses, Licensed Practical Nurses, and Home Health Aides), Home Service Aides, Medical Social Workers, Chaplains, Counselors, Dietitians, Therapists, Volunteers, Hospice Medical Director (supervision of your medical care), Pharmacists (supervision of your medications).

Some of the hospice professionals may provide services by directly visiting with the patient and family and some may provide services from the hospice's offices. The hospice benefit also provides for all the medicines, equipment, treatments, and supplies which are needed to manage the symptoms of your terminal illness and help your loved one to be comfortable.

**The four Levels of Care hospices provide are:**

- General Routine Home Care
- Respite Care
- Continuous Nursing Care in your own home (if you have symptoms which are uncontrolled and cause a crisis)
- General Inpatient Care in a hospice facility, hospital or nursing home (under arrangement between the hospice and facility)

The actual level of care your loved one receives depends upon his or her condition. As your loved one's condition changes, the level of care must change if needed to meet your loved one's and the family's needs.

The type of services and level of care your loved one receives depends upon your loved one's condition and changing needs. At the time of admission, the RN case manager will take note of the patient's symptoms, evaluate and assess the needs of the patient for various services and report to the attending physician what the patient's current status is and what orders may be needed to start hospice care services geared to the patient's

needs. The social worker and other professionals may also contact the physician for orders to provide the care which is their specialty.

The members of the Interdisciplinary Team will meet to discuss your loved one's care needs and how best to provide services which will meet his needs and the family's needs. The wishes of the patient and family regarding care must be taken into consideration and respected by the Interdisciplinary Team. Yet, the services provided must be "reasonable and necessary" under the regulations which govern hospice services. In other words, the services provided must be appropriate to help improve the comfort of the patient, manage symptoms, deal with other difficulties such as emotional distress, problems with coping, grieving, nutrition, problems the patient may have with routine tasks around the home (activities of daily living), and help with other problems all of which relate to the terminal illness.

## **THE HOSPICE PATIENT'S AND FAMILY'S ROLE AS PART OF THE INTERDISCIPLINARY TEAM**

The patient and family express their needs during the visits made by the hospice professionals. If the patient is unable to express in words how he feels and what his needs are, then the RN case manager and other team members carefully observe the patient for objective signs of the patient's condition. For example, pain cannot be hidden from an experienced and competent hospice nurse. There are nonverbal expressions of how the patient is feeling which the hospice RN case manager will especially be looking for.

The patient and family may directly speak with the hospice team members face to face, or they may also express their needs through phone calls. It is extremely important for the patient and family to communicate as fully as possible. Openly discussing your expectations from the very beginning will help the hospice team members to provide services which satisfy your needs. As the situation changes, it is increasingly important for you to express your needs clearly without reserve. Family members often become "protectors" or "advocates" for their loved ones. Who better to express your loved one's wishes, when she can no longer speak for herself?

It is often difficult for the family and/or patient to pay attention to the information provided by the hospice professional staff when the patient is first enrolled into the

hospice's program. However, it is very important for the patient and family to understand that information. Family members who are directly involved in assisting the patient with his care and/or decision making, must read the material and listen carefully, so that they have full information about the hospice's services.

All licensed and certified hospice agencies must provide care which meets the standards of care given in the federal and state regulations governing hospice care and must meet the patient's and family needs which are related to the terminal illness.

## **THE HOSPICE REGISTERED NURSE: CASE MANAGER**

The professional hospice nurse is a Registered Nurse with specialized training in evaluating and caring for the terminally ill patient and assisting their families. The hospice nurse must be an expert in listening, observing, communicating, and sensitively providing care under some of the most emotionally intense atmospheres imaginable. The RN case manager is the first and foremost contact the patient and family have with the hospice. It is the RN case manager who makes referrals to other hospice professionals and who contacts the physician for the initial medical orders.

The RN Case Manager will be constantly watching and observing changes which occur moment by moment in the terminally ill. After assessing the patient's signs and symptoms, she will create a plan of care along with the other hospice team members, and be responsible to reassess that plan of care in order to assure the comfort and management of symptoms which the patient may have. The RN may start medications based upon standing medical orders approved beforehand by the attending physician or upon new orders given by the attending physician.

The hospice RN supervises, teaches and directs other nursing staff. She is responsible for the care provided under her direction and nursing orders. She will administer medications, help manage symptoms, reassess the patient and consult with the physician as needed, and teach the patient and family about the nursing care and medications being provided. She may teach the patient and family how to continue to give medications when she is not there. If you need services which the hospice is not yet providing, your first step is to speak directly with your loved one's RN case manager.

## HOME HEALTH AIDES AND HOMEMAKER SERVICES

The hospice Home Health Aide (or sometimes "CNA" for certified nursing assistant) provides basic bedside care for the patient. The Home Health Aide will often be the Team member who actually spends the most time with the hospice patient and family, because they are providing the basic care in the home (or facility) and helping the patient with the routine activities of daily living (ADLs).

The home health aide reports directly to the RN case manager (and LPN) and must follow the plan of care and nursing orders made by the RN case manager. The home health aide will make regular visits to the patient and family, provide help as needed for bathing, dressing, and eating, for example. She checks the patient's vital signs (heart rate, breathing rate, temperature and blood pressure) and also reports immediately to the RN case manager if there are any significant changes in the patient's condition.

The home health aide will help to transfer the patient from bed to chair or sofa, into the bathroom or other areas. The home health aide, along with other staff will share techniques for safely transferring the patient. However, it is the RN case manager's responsibility for teaching the patient and family. A physical therapist may also explain safe transfer techniques to the family and patient.

Hospice *Homemakers* help to keep the patient's care area clean, neat and safe. The homemaker may provide cleaning services, grocery shopping or other errands. The homemaker may also run errands for the patient and/or family. If the area where your loved one is staying needs cleaning, you may ask the RN case manager to have a hospice homemaker sent out to your home.

## **MEDICAL SOCIAL WORK SERVICES: MANY SERVICES AVAILABLE**

Hospice social workers are an important part of the hospice services available to you and work as part of the hospice team.<sup>(13)</sup> Hospice social workers evaluate the needs of the patient and the family upon admission to the hospice program and may visit with you regularly as needed. Dealing with a terminal illness involves more than symptom management and patient comfort: it involves changing roles within the family unit, added responsibilities to family members, major decisions concerning care of the patient, increased concerns about financial matters and legal issues regarding advanced directives about care of the patient, wills, plans for the future, possible needs to relocate and so on.

Social workers are trained professionals who specialize in helping patients and families work through the many changes that occur as our loved ones health declines and eventually pass on. Hospice social workers are focused on respecting your wishes and the wishes of the patient as a whole. They can help you access needed resources in the community for financial or legal assistance or help you get the information you need to make informed decisions about the present and the future. Social workers must advocate for your needs and rights and help you meet the goals which are part of your plan of care.

Remember, the hospice plan of care includes the family unit as well as the patient. Psychological, emotional and spiritual needs are also important parts of the plan of care. The social worker provides information and counseling which can help the patient make his or her own decisions about where and how they wish to spend their last days (whether at home or in a facility, whether to use artificial feeding methods such as feeding tubes or not, and so on). Each patient's circumstances vary from another's, but everyone will have some major decisions to make. The social worker's role is not to impose any particular agenda, but to provide information about options, support your wishes and facilitate the process.

The social worker may act as counselor and hospice therapist for those experiencing tremendous emotional grief. She may help you to work through the waves of feeling that may be overwhelming. In some hospices, counseling may be provided by other therapists as well as the social worker. The goal is to make the most of the time left together with the patient and to build a strong foundation for the future with all its changes. Feelings of loneliness, anxiety or fear are common, and the social worker is experienced in helping you recognize, express and deal with your feelings constructively.

Hospice social workers or other specially trained counselors may provide bereavement counseling for up to 13 months following the death of the hospice patient.

## **SPIRITUAL COUNSELING: HOSPICE CHAPLAIN OR THE RELIGIOUS COUNSELOR OF YOUR CHOICE**

Approaching death has a way of sobering all of us and so it is quite normal for many to re-evaluate their beliefs about life, religion and what happens after death. Hospice offers support at this time of questioning. Questioning why this illness occurred, where to find the strength to face all the challenges, how to face life without our loved one at our side ... all of these questions and many more relentlessly confront us.

Hospice spiritual counselors can help you work through emotions and questions about your loved one's impending death, the meaning of life and other questions you may be wrestling with. Whatever your belief, hospice staff will be there at your side to listen and support you. Hospices have ministers on staff (or on call) who are especially trained in dealing with the grief that arises when dealing with a terminal illness, and staff will assist you to find a spiritual counselor of your own religious denomination.

Some families have not attended religious services for quite a while yet feel a need for spiritual guidance at these times. Each hospice usually has arrangements with local priests, ministers or rabbis who may be called in to assist the patients and families. If you want this type of assistance simply let the staff know and arrangements will be made. Hospice chaplains can also provide much insight and uplifting comfort. Even if you have no religious orientation, you still may wish to speak with the chaplain, and that is "ok" too.

## **HOSPICE VOLUNTEER SERVICES**

The hospice volunteer may provide a wide range of services. In all cases, the volunteer must be "oriented" and trained as a hospice volunteer in order to be approved to come out to the patient's home location and assist. Depending on the hospice agency which your loved one is enrolled in, there may be volunteer nurses, doctors, social workers, therapists and other non-professional volunteers. In the case of some un-certified/unlicensed hospices, the entire hospice team may be made up of volunteers. The hospice industry started out as a mostly volunteer hospice service. However, today most hospices are

licensed and certified and the hospice team members are paid professionals. The volunteer services of a hospice are actually required by the Medicare federal standards of care.

Volunteers may sit with your loved one while you go out. They may go shopping for you, run errands, listen and help. They can help prepare meals, read for your loved one and do many other tasks to help out. Volunteers are a very important part of the hospice team. Sometimes it is the help that volunteers provide that can help make it possible for your loved one to remain at home till the very end.

## **THE HOSPICE MEDICAL DIRECTOR AT YOUR SERVICE**

Each hospice has a medical director who is a physician. The medical director has an obligation to make sure that each hospice patient receives all the medically indicated services needed to control the symptoms of the patient's terminal illness. According to the federal regulations (42 CFR 418.54), the medical director "assumes overall responsibility for the medical component of the hospice's patient care program." Quite often the medical director has much experience in treating the symptoms of the terminally ill and can be a valuable resource to the patient, the family and hospice staff in managing the symptoms that arise from time to time.

Although each patient has his own attending physician, the patients also have access to the medical director of the hospice if there is any problem in obtaining control of the symptoms. The medical director serves as a secondary check on the attending physician to make sure that the patient receives the very best of care. In some instances an attending physician may not order the medications needed for the patient's comfort or to control the symptoms adequately. The RN case manager will communicate the patient's needs to the attending physician. If the attending physician refuses to provide for the patient's needs, the medical director should be consulted to intervene on the patient's behalf.

Part of the benefit of utilizing hospice services is the extra assurance that the patient will be kept as comfortable as possible. The hospice Interdisciplinary team creates a plan of care to assure the patient's comfort. The hospice medical director is an important member of the Interdisciplinary Team and can order changes on the plan of care for each patient.

If your loved one is not getting what he or she needs for management of symptoms and pain control, insist on speaking with the hospice medical director directly. It is your right.

## **COUNSELING AND THERAPY AVAILABLE IN HOSPICES**

There are many counseling and therapy services available in hospice, including social worker services, chaplain or spiritual care services, bereavement counseling, dietitian services and other services which may be needed by the patient and/or family/care givers. Hospices are required to provide Occupational Therapy, Physical Therapy and Speech-Language Therapy when the patient would benefit from those services.

You have the right to request these services and to receive these services. Your RN case manager may recommend one of these services depending on her assessment of the needs. Your physician will approve (order) the provision of these services if you need them. Many patients and families may feel unsure about using these services because they're unfamiliar with them. However these fears are usually quite unfounded, and counselors can help to make the total difference in your quality of life as the days unfold.

Social workers are licensed and extensively trained to counsel patients. The social workers used in hospice are specialists in "medical social work." They are familiar with the issues that confront families dealing with a terminal illness, and are prepared to help you take care of whatever issues confront you. In some cases families may be confronted with confusing documents and forms which need to be filled out. Others may have needs for financial assistance or have difficulties understanding correspondence or bills that have been left unpaid. There is often some "unfinished business" which needs to be taken care of.

In other situations, there is emotional/psychological "unfinished business" which needs attending to. The social workers are trained in helping you get through these demanding times and in healing some of the emotional difficulties you may be going through. Depending on your preferences and beliefs about religion, a priest, minister, or rabbi may be made available if you do not have a spiritual counselor of your own or if you have not been to church or temple services for years.

For those patients who have nutritional difficulties dietitians are available. When a patient has difficulties with nausea or vomiting, the physician may order medications to control those symptoms. In addition, a dietitian can recommend foods or drinks that will be easier to tolerate or different methods of food preparation which may also be helpful to the patient. Minimizing nausea and vomiting will help the patient to feel better and increase his or her strength. A dietitian may also be called in to evaluate the patient's nutritional status and provide information which can assist the physician in making decisions about the patient's nutrition.

## **DIETITIAN SERVICES FOR OPTIMUM NUTRITION**

Hospice dietitians assist the patient in achieving the best nutritional intake possible given the current state of his or her health. Dietitians have much experience in dealing with the obstacles to eating that often challenge the terminally ill. In conjunction with the physician, the dietitian may make suggestions about food types that are more appetizing to the patient or ways of preparing or serving the food that make it possible for the patient to eat.

Any patient who enters hospice must be evaluated at the time of admission to the hospice program, and if there is a dietary need, a dietitian should be provided to assist and educate the patient and family. Common problems such as nausea and vomiting are controlled with medications in some cases, while for others, a change of diet is sufficient. Hospice patients and families need to be aware of the changes occurring in the patient's body. Each disease process has different effects on the patient.

Many patients experience some alteration in their food intake during the course of their illness. It is common for the patient to reduce his or her intake as time passes and to choose different foods. With a terminal illness there are changes which occur in the patient's metabolism, the way he or she processes food and the general activity of the body which maintains itself in good health. The normal process of taking in nutrients and building up the body's cells, tissues and organs is part of a normal metabolism.

With a terminal illness, there comes a time when the body is no longer creating new cells and building up the body. Cells and tissues begin to break down in what is called a

"catabolic" state of metabolism. At this point, the body is no longer taking in nutrients even if food is taken into the stomach by whatever means. If patients are forced to take in food at this time, the body may simply refuse to take it in and reject it, through vomiting or diarrhea. A dietitian or the RN case manager will explain when this point is reached. However, withholding food before a patient reaches this state is not appropriate. The way to know the difference is to listen to the patient and then determine if there is any appetite or if there is an ability to take the food in and retain it.

If you have any questions about your loved one's nutritional intake, ask the hospice RN case manager for information, and if appropriate, she will arrange for the dietitian to visit and assess the patient's dietary needs.

## **OCCUPATIONAL, PHYSICAL, AND SPEECH-LANGUAGE THERAPY**

The hospice benefit specifically provides occupational therapy services, physical therapy services, and speech-language therapy services for those hospice patients that would benefit from such therapy. Simply having a terminal illness does not mean that we have to "give up" and lay down in bed and immediately die, as some may believe. Those patients who make the most of their remaining time usually experience the highest quality of life. Hospice is about improving the quality of life and providing comfort care, even if a "cure" for the disease cannot be made. What benefit would these therapies have for your loved one? Many. First of all, these therapists are highly trained specialists in their field.

### **Occupational Therapy**

An Occupational Therapist can evaluate the ability of your loved one to accomplish his activities of daily living ... to do the normal everyday tasks that are commonly performed, such as bathing, getting dressed, brushing his teeth, and feeding himself, etc. If there are difficulties in performing these types of tasks, the therapist can devise alternative ways of accomplishing these tasks which allow the patient to remain more independent (and less

dependent upon others) which can often help tremendously with the patient's self-esteem and attitude.

Sometimes different adaptive or assistive devices are used to help patients accomplish these tasks. The therapist can explain how your loved one can conserve his energy by doing things in an easier manner. Helping your loved one continue to do as much as possible (if he or she wishes to do so) can dramatically improve his quality of life.

### Physical Therapy

The physical therapist can evaluate your loved one's ability to move around safely in the home or facility. The therapist will determine what problems your loved one may be experiencing in getting around: walking (if applicable), in and out of bed, transfer from chair to bed, into the bathroom, to and from a car or wheelchair. The therapist can assess the patient's level of pain and provide physical therapies which can help to reduce pain. Strengthening exercises may be given if your loved one would benefit from these, and the therapist can evaluate all the equipment or layout of your loved one's living situation to make it safe and easily accessible.

### Speech-Language Therapy

The speech language therapist is especially trained in helping your loved one who might be experiencing difficulties in swallowing food, speaking or communicating in any way. The therapist can help the patient to better communicate and determine what types of foods or food textures are best. For example, some patients who have difficulty swallowing can safely swallow soft or blended foods or foods cooked in different ways. Making sure that your loved one is able to overcome swallowing problems could help your loved one live longer and would certainly improve his quality of life! If your loved one had difficulty speaking or could no longer speak at all, the therapist can help create alternative ways of communicating. Communication between the family members and the hospice patient is so important at the end of life. Unfinished family "business" (relationship issues) can be resolved and your love can be expressed and shared.

## Warning about Lack of Therapy Services

Ethical hospices will definitely provide these types of very important services to their patients. The RN case manager will make a referral to the therapists to come out and assess the patient's situation and to determine what therapy might be beneficial for your loved one.

However, you should be aware that there are many hospices that do not properly inform the patient about these services and simply do not provide them, or actually misinform the patients and families by stating that these types of services are not part of the hospice benefit! We have gotten repeated complaints here at Hospice Patients Alliance, from families who reported having been told by hospice staff that these services were not available and not part of hospice. These therapy services are part of the hospice benefit!

## Federal Law Requiring Provision of Therapy Services

The following is the exact language of the federal law governing hospice care at the Code of Federal Regulations, 42 CFR ch. iv. part 418:

### Subpart E--Conditions of Participation: Other Services

Sec. 418.92 Condition of participation--Physical therapy, occupational therapy, and speech-language pathology.

(a) Physical therapy services, occupational therapy services, and speech-language pathology services must be available, and when provided, offered in a manner consistent with accepted standards of practice.

If you have difficulty obtaining these types of services for your loved one, simply print out this page and show it to your RN case manager. If they still refuse to provide therapy services, you can speak with the hospice director or file a complaint with your State licensing and certification department.

## **BEREAVEMENT SERVICES: DEALING WITH GRIEF**

Grieving for the loss of our loved ones begins even before the actual time of death:

We grieve for loss of the relationship, loss of the interaction, loss of all types of support that our loved ones have given us;

We grieve for the changes that occurred in our loved one's life and the suffering that he or she may have gone through;

We grieve for the end of the opportunity to do the things we wanted to do together,

And we grieve at the ending of the connection with that person here on Earth,

... the ability to communicate immediately and directly,

We grieve for the end of a life together as we knew it, not knowing the changes to come.

Grief is more than sadness, it may feel overwhelming and consuming. However, grieving is a healthy and natural reaction, and all of us go through it at one time or another. It is part of life, just as the death of this body is common to all of us. It is said that the loss of a loved one is "something that you may get used to, but you do not necessarily totally get over it." We learn to cope with it.

But grieving can lead to depression and ineffective coping. Hospices must provide bereavement support services and counseling to all family members for up to one year after the death of the hospice patient.<sup>(14)</sup> This includes children as well as parents and spouses as well as siblings. The hospice counselors will evaluate the family to determine who may have a greater need for bereavement counseling. This counseling may be in the family's home or at another meeting place; the important thing to remember is that the hospice benefit includes support even after the time of your loved one's death (for up to a year after). The hospice must contact you and arrange for the bereavement services you need. This is part of why hospice is considered wholistic; it includes the needs of the whole person, the whole family unit and considers your needs on psychological and emotional levels, as well as the spiritual.

If you are feeling a need for support, please communicate that with the hospice social worker, chaplain or RN case manager. They can arrange for the support you need to help you get through this difficult time. If you notice that another family member appears to be having a difficult time, then you should also contact your hospice representative to arrange for support. Sometimes people, especially children, are unable to express their feelings and needs openly perhaps because they do not know how to put those feelings

into words. With children performance in school may be affected or behavioral problems may crop up. Hospice is there to help you before, during and after the time of death.

## **HOSPICE PHARMACIST SERVICES**

The hospice pharmacist works mostly "behind the scenes" at the hospice agency's offices or at a pharmacy under contract with the hospice to provide medications for its hospice patients. Considering the types of medicines prescribed for the terminally ill, the hospice pharmacist must be especially careful in the management of the controlled substances used, such as narcotics or other controlled medications.

Pharmacists often have the ability to catch potentially harmful medication combinations which others may miss or not be aware of. They will be able to see a list of all medications being given to your loved one and will then be able to recognize medications which perhaps may not be given together. Sometimes a physician will add on another medication without reviewing the entire list of medications which the patient may be receiving. The pharmacist is a great "check and balance" for the administration of medications to the hospice patient.

## **FINANCIAL ASSISTANCE AVAILABLE TO YOU FOR HOSPICE SERVICES**

Whether you are covered by Medicare, Medicaid, general government-run healthcare or private insurance, hospice services are available to you. If you do not have any health care coverage, many nonprofit charitable hospices will make their services available anyway. When the public makes charitable donations to a nonprofit hospice part of that money is reserved for such charitable services. Even the homeless receive hospice services from the charitable work of many hospices. If you have questions about paying

for hospice, and you have private insurance, check with your insurance company's customer service answer line. Many companies do provide coverage for hospice.

If you are covered by Medicare Part A, you should know that there is a specific "Hospice Benefit" paid for by Medicare which covers all services, medications and equipment required which are needed for care related to the terminal illness. If you happen to have more than one illness, Medicare should continue to pay for the other services needed to treat those other medical conditions. (See "Medicare, Medicaid and Private Insurance" - Section 4a of this text).

If you find that you do not have coverage from a private insurance policy, check with more than one hospice to see which one will provide services to you. The local yellow pages may be helpful. If you live in a remote area and cannot find a local hospice to assist you, you might try contacting a nonprofit charitable hospice in a nearby city.

## **MEDICARE, MEDICAID, GOVERNMENT-RUN HEALTHCARE AND PRIVATE INSURANCE**

The major sources of payment for hospice care are Medicare, Medicaid and private insurance, although Medicare certainly provides for the larger segment of the hospice population. Which source of payment covers for your hospice services should have little effect on the type and quality of services you will receive.

Any hospice which receives reimbursement from Medicare or Medicaid must be licensed and certified by the State agency which surveys and inspects health care agencies. If the hospice is part of a national or regional corporation, the location where the hospice actually provides services determines which State performs these inspections. Most private insurers require the hospices to meet the same requirements as do Medicare and Medicaid, and to provide the same set of services included in the standard "Hospice Benefit."

There is an additional benefit to having a private insurance company cover your hospice services: you have an insurance company "case manager" who reviews the services needed by the patient and family and the services being provided by the hospice. Unfortunately, some hospices do not provide all the services you are entitled to! If this

occurs in your situation, you need to be assertive and speak with the RN case manager, the hospice's director or the hospice medical director.

If you still experience any difficulty getting the hospice to provide adequate services, do not hesitate to call your insurance company's "case manager." They can "go to bat" for you to get you the services you need. If the hospice still refuses to provide the services you need consider switching hospices. Even though these hospices may suggest that care will suffer if you switch, the transition to another hospice is usually quite smooth. Staying with a hospice that is not providing the services needed for your loved one's comfort defeats the very purpose of having the hospice. Some hospices will "back down" and provide what you need if you let them know that you will switch if proper care is not provided.

Do not be fooled by "threats" that hospice services will be interrupted or that "it is not possible" to switch at this time." Nonsense. You always have the right to choose whichever physician you wish and change at any time within one hospice certification period; you always have the right to switch hospices (once within a hospice certification period) to get the services you are entitled to! If you do switch physicians or hospices, the hospice must assure a smooth transition and continuity of services throughout the change.

Because the federal and state governments wish to "get their money's worth" for the funds they pay out to the hospices, it is important to report any hospices who do not provide the full set of services needed to meet the patient's needs. Since Medicare and Medicaid pay a hospice on a "per-diem" or daily basis for all the services needed, the hospice is receiving payment on the assumption that it will actually provide all needed services. When a hospice does not provide services needed and which you are entitled to, that hospice may be involved in "health care fraud." You can help stop the rampant exploitation of the Medicare and Medicaid systems by unscrupulous administrators. Report these violations to the Office of the Inspector General (see "Links to Report Fraud in Hospice").

**ASSISTANCE IF YOU DON'T HAVE MEDICARE,  
MEDICAID, GOVERNMENT OR PRIVATE INSURANCE**

For an ever increasing number of the "working poor," health insurance coverage is becoming harder to obtain. Many family breadwinners are working at part-time jobs without health care benefits, and the trend for employers to cut back on these benefits may continue as competition among businesses continues to be quite strong. Even if you do not have any health care coverage, you can still obtain hospice services from many hospice agencies.

A large number of hospices are charitable, nonprofit corporations which receive charitable donations from other corporations, charitable organizations such as United Way, or from private individuals in the community. These donations are often used to help the hospice provide services for those patients who cannot pay and do not have health insurance coverage.

If you personally need hospice care or know of someone who does need this care, contact hospice agencies in your area and ask them if they provide hospice services on a charitable basis. You should be able to find assistance from one of the hospices in your area.

## **WHAT SERVICES YOU CAN EXPECT**

Hospices can provide a full range of services including visits on a regular basis by a registered nurse, home health aide visits, social worker and chaplain visits, therapy if needed to promote the quality of life (physical therapy, occupational therapy or speech and language therapy. Dietitians and other counselors may be available as well. Basically, hospices are required to provide the services which the patient and the family need to meet their needs related to the terminal illness. It is important to realize that the family is included in the equation of what services are to be provided, because the hospice benefit is geared toward the patient and family as a unit. When there is a change in the hospice patient, it affects the family as well, and problems in the family affect the patient. Hospice is there to support you through these times and help make the quality of life the very best possible under the circumstances.

If there is a crisis in which the patient's symptoms are uncontrolled, you can expect to have around the clock nursing in your own home for brief periods (up to 3 days). In the case of a facility, twenty-four hour staffing is always available for patient care. If you

experience any problem getting symptoms under control and the attending physician is refusing to provide needed medications, you can always ask the hospice medical director to intervene.

Hospices exist to provide the end-of-life care that you and the family need to keep the patient comfortable and help everyone involved cope with all these changes. After death hospices must provide bereavement counseling for up to one year.

## **LIABILITY FOR PAYMENT FOR COVERED AND NON-COVERED EXPENSES**

Normally, families of hospice patients would not be receiving bills for hospice services since hospices receive reimbursement for those covered hospice services from Medicare or private insurance. However, in some instances, families of hospice patients are receiving bills, and they are often confused by these bills. In certain cases, the bills are actually improper and are attempts by a hospice to get paid twice for the same services (fraud). Sometimes the bills are completely proper. Families ask whether or not they have to pay for these bills relating to services, equipment, medications, or other items provided to their loved one.

Services, equipment, medications and other items fall into two main categories which need to be understood: Covered Services and "Non-Covered Services." Hospices are responsible to pay for the expenses of all *covered* hospice services out of the reimbursement they receive from the Medicare program or other insurance company. For example, the hospice itself must pay for all medications which are used to manage symptoms which are *due to the terminal illness*. The hospice may charge a small co-payment of up to \$5.- per prescription.

Any covered services which are included as part of hospice cannot be billed to the patient or family by a hospice. If the hospice did so, and some "rogue" hospices are doing so, that would be health care fraud. Why? Because it would amount to billing twice for the same set of services: getting paid by Medicare or another insurance company first, and then getting paid again (for the same services) by the patient and family.

## **Hospice Billing Others for Covered Services Is Prohibited**

The Medicare Hospice Manual, Publication 21, chapter 4, reimbursement for hospice care states at Section 411:

"Section 1866 of the Social Security Act requires providers (including hospice providers) to file an agreement with the Secretary of Health and Human Services in order to be qualified to participate and to be eligible for payment under the Medicare program. In this agreement, the hospice agrees not to charge (and accordingly may not charge) any individual or any other person for items or services for which the individual is entitled to have payment made under the hospice provision. ... a hospice may not bill a third party such as an insurance company ... for covered palliative drugs and biologicals for which payment is made through the Medicare rates."

"If a hospice furnishes, at the request of a beneficiary, items or services in addition to those that are covered under the hospice provision, the hospice may charge the beneficiary for these items or services. [emphasis added]"

## **Written Notice Required Before Services Provided**

A hospice must provide written notice to the patient and family before providing any service that the hospice intends to charge the patient and family for. And, the hospice can only properly bill for services which are not covered under the hospice benefit. This means that if the hospice wishes to bill you for any non-covered services or other items, it must truly inform you (and do so in writing) that it will charge you for those services, before the service, equipment or other item is provided.

Even if the hospice inaccurately tells you that the service is "not covered" (and therefore they claim that they can charge you), and it actually is covered, the hospice still has to

provide written notice to you beforehand that they intend to bill you for the service. Then, you would have, in writing, a notice that they would be billing you for services which are covered and for which they are not allowed to bill. So, hospices that are improperly billing for actually covered services do not normally provide written notice beforehand that they intend to bill you; they just send a bill and hope to get paid by you and Medicare as well! In any case, a hospice cannot "surprise" you after the services, equipment or other items were provided and just send you a bill "out of the blue" without providing written notice beforehand.

The Medicare Hospice Manual from the Health Care Financing Administration (HCFA) Publication 21 (although this is an old manual, the principles contained in it still apply) states :

Chapter 2, Eligibility and Coverage, Section 274.1, "Notifying Patient of Noncoverage"

"If you are aware that the services furnished a patient are not covered, advise the patient (or his representative) in writing prior to or at the time of start of care (or at the time the type of care changes) that the care is non-covered and that no claim for Medicare reimbursement will be submitted."

If you have questions about any bills you receive for hospice services, first try to determine if the services, equipment or other items are "covered" services or not. If the bill is for hospice services which are definitely covered under the Medicare or insurance benefit, the hospice is not permitted to bill you for those services! You may wish to contact the hospice's billing staff and hospice director to discuss the bill.

If the hospice insists that you pay for services which are part of the hospice benefit, even after you question those charges, you may wish to file a complaint to the U.S. Office Of Inspector General. See the section on "Links to Report Fraud."

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## **FOUR LEVELS OF CARE YOU'RE ENTITLED TO RECEIVE**

There are 4 levels of hospice care which are required Services:

- Routine Home Care
- Continuous Nursing Care at Home
- InPatient Level of Care in a Facility
- Respite Care

Each level of hospice care must be provided if the patient's and family's needs require it. If, for example, the family is exhausted after providing care to the patient, the hospice must provide "respite care," (up to 5 days at a time) to relieve the family and give them a break in order to rest. If the patient is not having uncontrolled symptoms at home, then the patient is placed on "routine home care" services. If the symptoms become out of control, then the hospice must provide "Continuous Nursing Care" in home. If the patient has symptoms out of control and is already residing in a hospice facility, then the patient is placed on "inpatient care."

The hospice must inform you about all these levels of care when you are considering "admission" to the hospice's services and then when you sign the "informed consent" form. If the hospice's "informed consent" form does not clearly list the four levels of care, think carefully about whether or not you wish to use that hospice's services!! A hospice that clearly list the four levels of care is more likely to provide the required services, especially if you request the service and remind them that "it is right here in writing."

## **CONTINUOUS NURSING CARE AT HOME**

Most people in the U.S. think of hospice as a resource to help the terminally stay at home to die. Hospice has been and is generally oriented around home-based care in the United States. In England hospice started out as a facility-based service with most patients entering a facility. Now, in both countries, there is movement toward a middle ground where patients and families can access services of both types, depending upon their wishes. If you choose to stay home, the hospice must provide services to you in your own home. One exception to this rule is if the hospice is so small (less than 7 employees) and is in a rural/non-metropolitan area and does not have the staff to provide Continuous Nursing Care in your home. For most hospices, it must provide the service. If it does not, a violation of the standards has most likely occurred.

In the U.S.A., there are four levels of care that are "required services" which must be provided under specific circumstances. The four levels of care are: ROUTINE HOME

CARE, RESPITE CARE, INPATIENT CARE AND CONTINUOUS NURSING CARE (in home). Continuous around the clock nursing care in your own home is your right if the patient is having symptoms which are "out of control." This standard of care applies whether you reside in your own home in the community, a foster care home, assisted living facility, apartment or even a nursing home ... all of these locations are considered "your own home." This is one of the advantages of signing up for hospice, and you are entitled to these services.

If you sign up for hospice care in a nursing home and the symptoms become uncontrolled, the hospice must provide extra staff to assist and make sure that patient comfort is regained and symptoms are controlled. This is especially important in nursing homes when the patient is in severe pain. Many nursing home staff are often reluctant to administer the strong narcotic pain medications needed to control severe pain and have not been trained in dealing with these medications.

Some nursing home staff do not understand the medical management of severe pain. Hospice staff do understand, and they should be at the patient's bedside making sure the patient is kept comfortable. Whether or not the patient is covered by Medicare, Medicaid or private insurance, the standard for a licensed and certified hospice is the same.

Understanding the four levels of care is crucial to your understanding which services you are entitled to receive. When a patient enters hospice, the patient's condition must be evaluated by a registered nurse who, in consultation with the attending physician, will prepare an initial "Plan of Care." If you choose to stay at home and there is no current "crisis" due to uncontrolled symptoms or other situations, the patient is placed at the "routine home care" level of care. Routine home care services include periodic visits by the registered nurse, home health aides, social workers and counselors, as required by patient and family need.

When symptoms become "out of control" and the symptoms cannot be controlled by routine home care services, the hospice must provide around the clock nursing care in your own home; they must make a "good faith" effort to control the symptoms at home! They cannot force you into their hospice facility against your will. (This has happened to some patients who wished to die at home). These continuous nursing services are based on patient and family need and must be staffed by licensed nurses at least 50% of the time. This means that when you get 24 hours of nursing at home, at least 12 hours must be directly provided by a licensed nurse, not a home health aide! Home health aides cannot give medications, especially controlled substances such as narcotics for pain relief. If the patient requires these medications, licensed personnel or the family must give them.

Types of symptoms that might require Continuous Nursing Care at home include uncontrolled:

- Severe pain
- unrelenting nausea and vomiting
- "terminal restlessness" or agitation
- bleeding
- acute respiratory distress
- seizure activity
- and many other symptoms.

If you are covered under Medicare or Medicaid, regulations state that the hospice must provide Continuous Nursing Care for brief periods, (a common time period is up to 72 hours). It is the RNs duty to re-evaluate the need for Continuous Nursing Care each day. The hospice may continue the care if symptoms are still uncontrolled. If you are covered by private insurance, most likely your insurer covers Continuous Nursing Care in the home; then the hospice must provide the care in your own home. Many private insurers will pay for Continuous Nursing Care in your own home for periods longer than 3 days.

What if the hospice then says that it "doesn't have the staff" to continue the care in your own home? Then the hospice is allowed to subcontract out nursing services to another agency (such as a home health care agency), but it must provide some orientation to hospice care to that agency. You may need to insist that your wishes are respected and honored by the hospice. It is important for hospices to have an ongoing relationship with another home health care agency if it is foreseeable that a need may arise for subcontracted nursing services.

Remember, it is the "squeaky wheel that gets the grease." So if you plan on staying home to be with family, make sure your wishes are clearly known to your case manager, social worker and attending physician. Do not let anyone manipulate you against your will into a facility! Insist that your legal right to Continuous Nursing Care services be honored and that you get the services you are entitled to receive. Whether it is Medicare, Medicaid or private insurance, you and the general public have paid for this care through taxes or insurance premiums.

# **INPATIENT CARE LEVEL OF SERVICES IN A FACILITY**

When the patient's symptoms become uncontrolled, hospices are set up to take an aggressive approach to overcoming these barriers to patient comfort. Hospices must assure the patient's comfort and if the patient resides in the hospice facility, extra staff or attention will be provided to make sure the patient's needs are met. In some instances, the patient may be temporarily placed in an acute care hospital (transferred from his home) if there is no hospice facility. This level of care is called "Inpatient Level of Care" and the hospice is reimbursed at three times the level that it receives when the patient is receiving the usual "Routine Home Care Level of Services."

At this level of care, you can expect individualized attention in an intense and moment to moment assessment of what is occurring and what needs to be done. There is often very close coordination between the hospice staff and the patient's attending physician who together work to achieve patient comfort. Medications may be changed or dosages may be adjusted, or ways of administering medications may be changed to attain an optimum effectiveness of the medications: all geared to helping the patient to be comfortable.

If your loved one is already residing in a hospice facility and the symptoms are uncontrolled, you can inquire about placing the patient on "In Patient Level of Services" so that he or she can get the special attention that may be required. This is especially important if you think your loved one's needs are being ignored.

If the hospice appears short-staffed you need to speak with the RN in charge at the facility, then the facility's director, and if that is not effective, speak with the director of the entire hospice. Ask the director what they are doing to correct the situation. If the situation is not corrected within a day or so, even after speaking with the hospice's director, then a complaint to your State's division of health facility licensing and certification is in order. You certainly cannot wait for a month or two while they tell you they're "trying" to hire someone.

The hospice is certainly getting paid to provide adequate care, and they are required to do so! Saving money on staff at your expense and suffering is not what hospice is about. Unfortunately, there are some hospices that do purposely under-staff their facilities and simultaneously pay their administrators handsomely ... just as in other areas of health care! Be assertive.

## **RESPITE CARE LEVEL OF SERVICES**

When the patient resides at home and the family has been providing much care for the patient, exhaustion may set in, and the family needs "a break." That is what respite care is all about. The patient is temporarily placed in a facility so that the family can get rest from the seemingly never-ending list of things to do which are part of the patient care routine.

Respite care is also a required service, which means that if the patient is willing and the family needs it, the hospice must provide a placement in a facility for the patient up to 5 days, after which the patient is transferred back home.

## **ROUTINE HOME CARE LEVEL OF SERVICES**

When a patient enrolls in a hospice program, there is a wide array of services which are to be provided. If the patient does not have symptoms which are out of control and which require Continuous Nursing Care, then the patient is placed on the Routine Home Care Level of Services. This level applies whether the patient resides in a facility or in his or her own home. Routine Home Care includes the following:

- RN Case manager visits
- Social Worker visits as needed
- Chaplain
- Home Health aide services
- Counselors (Dietitian or other if needed)
- Hospice Medical director
- Therapy if indicated
- Medications
- Equipment

All of the above are to be provided as needed to manage the terminal illness and help the patient maintain comfort. How often the registered nurse or social worker visits is determined by the needs of the patient. The hospice staff work together with the patient to create a plan of care which addresses the needs of the patient. Home health aides may visit once, twice or three times a week to help with bathing and activities of daily living ("ADL's").

Even with all the above services, you also have 24 hour access to hospice registered nurses who are "on-call" to answer questions and help you deal with situations that may arise after hours.

These services are part of the "hospice benefit" reimbursed by Medicare, Medicaid or private insurance.

If you are considering using a hospice, booklets or other printed literature may be available to help you understand the services provided. If you have additional questions about what services are provided by any hospice in your area, they will be happy to discuss their services when you contact them.

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## **KEEPING THE PATIENT COMFORTABLE: "SYMPTOM MANAGEMENT"**

One of the main reasons for using a hospice's service is represented by the term, "symptom management." With most terminal illnesses, symptoms arise which can be quite uncomfortable and which cause a lot of fear and confusion for both patients and families alike. Fortunately, hospice staff are thoroughly trained in how to achieve patient comfort. Using standing orders or medications ordered by the physician directly, hospice staff normally will do everything possible to keep your loved one comfortable.

Medical science has learned much over the years and even very severe pain can be controlled in most cases. If oral medications are not effective, the medication may be changed to another or the dosage increased or the route of giving the medication changed. Sometimes a patient may not be absorbing medications which are taken orally. The physician may order medications given "subcutaneously" or "intramuscularly" or even by "IV" (intravenously). The same dosage of medication given by IV may be twice as effective as if given by mouth!

In addition, there are small, portable pumps for IV infusions called "PCA's." These little devices can control the rate of giving the medication and also allow for "boluses" or little extra dosages of the medication, all controlled by the patient, family or nursing staff on hand. Using PCA's, many hospices can achieve pain control at home without a hospital placement being necessary to achieve pain control. In fact, almost all symptom control procedures which can be done in a hospital can also be done at home with no need for bothering the patient by moving him or her to a hospital.

Symptoms can be of many sorts, even though we've mentioned pain above as a common example. Some patients may have severe vomiting, hiccoughs, seizure activity, agitation or other disturbances. These symptoms may be common with a particular disease and are often anticipated by the hospice staff and the physician. Your RN case manager will keep you informed of what symptoms are beginning to make themselves known, and what measures can be taken to control them. Good hospice care at the Routine Home Care Level of Services can often avoid "emergencies" and "crisis" situations. The RN case manager will instruct you on how to administer these medications. Often, when a medication is begun for a symptom related to a terminal illness, that medication will need to be continued throughout the course of hospice care, but that is something which will be explained to you for each particular medication.

In those situations where an attending physician may be unwilling or unable to help your loved one be comfortable, you have the right to contact the hospice's medical director for his or her intervention on your loved one's behalf. The medical director must assure that your loved one receives the care needed to maintain comfort.

## **DO *not* RESUSCITATE ("DNR") ORDERS, POWER OF ATTORNEY FORMS, ADVANCED DIRECTIVES AND PATIENT COMFORT**

When a patient receives a diagnosis labeled "terminal," it goes without saying that the patient and family need to discuss the patient's wishes for medical care as time goes on and conditions change. Many patients and families hesitate to discuss these issues, because they wish to avoid discussing the idea of "death" or any serious change to the patient's condition. Avoidance and denial of the problems confronting them will not solve anything and can cause serious problems later on. That is why open discussions are

important. Although patients often have strong feelings and beliefs about end-of-life care, not all of them wish to discuss these matters. And not discussing these matters can result in their wishes not being honored or even known, when later on, the patient may have lapsed into an irreversible coma or other inability to communicate with doctors and family.

Without the advantages of hospice care, the outcomes may be even more troubling. In the 1998 RN Magazine survey of 743 hospital-based RNs, 26% "have seen a physician or other health care provider deliberately disregard an advance directive. 47% [of respondents to the survey] have seen the patient's family do the same." "Among those respondents working in critical care - the [Intensive Care Unit or Critical Care Unit] - that number jumps to more than half." (From the November, 1998 issue of RN Magazine, published by Medical Economics at Five Paragon Drive, P.O. Box 430, Montvale, New Jersey 07645).

Fortunately, hospices are specifically oriented to dealing with these issues and work hard to honor the wishes of the terminally-ill patient. Most hospices will ask the patient and family if they have finalized plans about end-of-life care (Advanced Directives) and whether or not the patient wishes to be "resuscitated" in the event his or her breathing or heart stop. If the patient does not wish to be resuscitated and has informed the physician, the physician can make a "Do Not Resuscitate" order, called a "DNR." There are many varieties of "DNR" orders. It is not a "black and white" issue, ... it is not a case of "either you resuscitate or you do not."

Some patients will choose to have medications administered, but no chest compressions. Others may choose to have chest compressions and rescue breathing but no special medications given. If you have even the slightest doubt about what you want, or if there is any conflict within the family, we strongly encourage you to seek legal advice from a professional attorney who practices in this area of law. By consulting an attorney, the patient can make sure his or her wishes are actually honored. Whether you have concerns about DNR forms or Powers of Attorney for business and legal matters, or for medical decisions, an attorney's advice can be quite helpful and help you to avoid major problems later on when it is "too late."

As mentioned, some patients will choose to have medical interventions involving medications or oxygen, while some will choose not to have CPR (cardiopulmonary resuscitation). Hospices cannot force you to sign a DNR form, but hospice staff are not employed to perform CPR ... the very heart of hospice is to keep the patient comfortable, but neither to "treat" the disease nor prolong life. In some hospices, the family itself must call the EMS (emergency medical system) if they wish to have EMS personnel resuscitate the patient.

From the hospice point of view, it makes sense to have Advanced Directives forms and a DNR form filled out which clearly states what the patient's wishes are, and to make those wishes known to the physician, family and hospice staff. "Advanced Directives forms" are also called "Durable Power of Attorney for Medical Care" in some locales. An ordinary "Power of Attorney" gives another person the legal right to sign checks and conduct business matters in your name or for you. The ordinary "Power of Attorney" does not give another person the legal right to make decisions about the medical care you do or do not receive. If you are unable to make these decisions on your own or to communicate your decisions, the decision will be made for you by your family in consultation with the Attending physician. Your wishes may not be followed! For this reason, a competent attorney should be consulted if you believe your family or health care workers may not honor your wishes regarding end of life care.

Only a "Durable Medical Power of Attorney" will authorize another person to make decisions in the place of the patient when the patient is unable to communicate his or her own wishes (due to a coma or other cause). If the patient is still able to communicate his or her wishes, the patient always retains the authority to make his or her own decisions. The Durable Power of Attorney for Medical Care only becomes effective if the patient is no longer able to communicate his or her wishes about medical care decisions. By making out a Durable Power of Attorney specifying who can speak on your behalf, and specifying in detail what your wishes actually are, your wishes are more likely to be carried out and family who may have been unaware of the patient's wishes, are less likely to interfere with the patient's wishes later on.

It should be realized that even one vocal family member can turn the dying process "upside down" and violate the patient's wishes if there is no DNR form filled out. Discussing your wishes with the family and physician and filling out the forms is the most important thing you can do to assure that your wishes are followed.

Patient comfort could be interrupted if a family member objects to the pain medications given to the patient, arguing with the physician that the patient is "over-sedated" or accuses the physician of "over-medicating" the patient. The physician may be afraid of being sued and may alter his treatment plan in order to "keep everybody happy," except that the patient himself may no longer be able to speak up for himself!

On the other hand, if there is no DNR form filled out, and a family member calls the EMS when the patient is at the point of death, the EMS personnel may be legally required to perform CPR even though the patient is in hospice and is "ready" to pass away. Performing CPR on a patient who has been terminally ill may be extremely painful to the patient and emotionally upsetting to the family. Making decisions ahead of time, filling

out Advanced Directive forms and using DNR forms to clarify the patient's wishes has many benefits, and it is important to realize, the patient can change his Advanced Directive or DNR form at any time, simply by making his wishes known to the physician, other hospice staff or other adults.

## **FLUID MANAGEMENT IN TERMINAL ILLNESSES**

Dealing with altered fluid management in the terminally ill may be one of the most difficult experiences for families of hospice patients. We all know that drinking adequate fluids is extremely important to our health. Our bodies are made up of large amounts of water. The blood has large amounts of water, and every cell in the body requires water to live. In the terminally ill, the amount of food taken in often decreases as the patient's appetite declines and the ability to process the food through digestion also decreases. Later on, many patients will also begin to drink less and less. Differences in patient's experiences will depend upon the type of illness they have.

For many families, giving food to a family member is an active expression of their love: "food is love." In certain cultures and religions, food holds an even higher place of reverence and refusing food or drink is contrary to all their beliefs. However, in the case of the terminally ill, providing food or liquids late in the dying process may actually harm the patient by causing fluid imbalances. If the patient's bodily systems and organs cannot handle the fluid, symptoms arise which interfere with the quality of life of the patient. The family is torn between giving the fluid (even if the patient does not want it) and withholding fluid which they believe will cause "dehydration."

Giving fluids against the patient's will is a violation of the patient's right to choose. Patients often know what they can or cannot handle, and they will drink if they can handle it. Patients who are ready to die and whose systems are shutting down, will naturally curb the food and fluids that they take in. Family members may have a hard time accepting this change, because the underlying belief is that "as long as he continues to eat or drink, he will continue to live." This is not true! If a disease process is causing declining appetite and thirst as the patient is approaching death, continuing to eat or drink will not only not prolong life, it could hasten death! There is a natural process of slowing winding down the body's metabolic processes: declining food and fluid intake is a natural consequence of the dying process and is not uncommon or to be fought.

In patients with cardiac or respiratory disease, problems with fluid management may be exponentially increased. What kinds of problems arise? Edema or swelling of the legs and arms may become a problem as "water" or fluid begins to collect in tissue spaces outside of the circulatory system's arteries and veins. Unnaturally high fluid levels in the tissues can result in poor healing and susceptibility to local infections in that area of the extremity. Elevating the extremities (usually feet and lower legs) may be helpful in some cases. Diuretics or "water pills" may also be prescribed by the physician.

However, edema of another sort can be quite upsetting and even more troublesome: "pulmonary edema" or "fluid in the lungs." Pulmonary edema occurs when fluid from the circulatory system begins to pool in the lungs, causing respiratory congestion, shortness of breath and impaired gas exchange resulting in not enough oxygen being taken in. Failure to take in enough oxygen can cause many problems including confusion, fatigue, anxiety, and even death. In some disease processes, pulmonary edema is a common symptom of approaching death. In cardiac disease, such as congestive heart failure ("CHF"), edema may occur in the extremities or the lungs, depending on which half of the heart is weakened. In right-sided heart failure, the blood circulating to the lungs brings added fluid to the lungs, while in left-sided heart failure, the blood circulating to the extremities brings added fluid to the arms and legs.

In cardiac disease, diuretics may not be sufficient to control pulmonary edema. Other medications such as scopolamine, atropine, hyoscyamine and/or morphine may be given. Morphine in combination with the diuretic: lasix (furosemide) is one of the most effective drug combinations of choice in cardiac-related pulmonary edema.

When pulmonary edema is caused by other than cardiac causes, scopolamine, atropine or hyoscyamine may be sufficient to "dry up" the unnaturally excessive secretions (or fluid) in the lungs and maintain patient comfort. Medications may be tried and dosages adjusted until the right combination and strength is found: medicine is an art as well as a science. One thing should be well understood by family members caring for the dying: if the symptom is caused by the terminal illness and nothing has changed to remove the cause of a symptom, then whatever medication the physician has ordered and which is being given must continue to be given, generally, up to the very end, if possible. This means, for example, that if the patient is having excessive fluid building up in the lungs and has taken a medication to "dry up the secretions," the cause has not been removed when the symptoms subside ... if the patient's breathing improves, it is only the medication's desired effect. Stopping the medication at this point will only cause the fluid to start building up again, and it may be much more difficult to get the symptoms under control later in the game!

If the lungs are filling up with fluid, and the patient is unable to swallow, giving medications under the tongue (sublingually) may sometimes add to the problem, because the fluid flows down into the lungs. In these cases, you may wish to inquire about giving the medications transdermally (by applying a medicated patch to the skin) or subcutaneously (by using tiny needles for injections, which are not painful).

Aggressive medicating of symptoms in the actively dying process is a key to keeping the patient comfortable. Removing needed medications from the actively dying can cause an extreme crisis and unnecessary suffering for the patient and all involved. If you have any questions about how to administer these medications, ask the RN case manager who will be more than willing to explain "symptom management" to you.

Hospice staff have observed some families literally "forcing" fluid down dying patient's throats, against the advice of hospice staff and the physician. In these instances, the patient basically "drowns" to death, even though he or she may be in a coma. Patients who are lethargic, stuporous or even in a coma cannot drink anything! Drops of fluid such as found in liquid oral medicines may be given in very small amounts. Anything that causes the patient to cough, or that may go into the lungs, may not be given without serious adverse results. If the patient is not conscious enough to cough or swallow, fluid given will certainly make its way into the lungs ("aspiration") causing "aspiration pneumonia" and likely hastened death. If you have questions about whether or not your loved one can take in liquids, you should contact your RN case manager for advice.

If you have difficulty with the idea of not giving food or fluid for a loved one, when he or she cannot even swallow or take it in without difficulty, discuss it with your physician or the hospice RN case manager, social worker or chaplain. There is a time to let go, and let the natural process of dying occur. The most peaceful and comfortable death for the patient is when medications are given which control the symptoms and nothing is forced upon the patient. There is a time to live and a time to die. Respecting the dying process, accepting the dying process, and loving the person who is dying, are all part of the same process. Letting go does not mean that you do not love; it simply means that you are being realistic and compassionate toward the dying. By not interfering with the natural changes that occur in the dying, you can help your loved one die in peace and with dignity.

# **FOOD, NUTRITION, ARTIFICIAL FEEDING METHODS, CONSTIPATION AND QUALITY OF LIFE ISSUES**

## **Food & Metabolism**

When appetite declines and your loved one is refusing food, it is quite difficult to accept. We all know that you have to eat to live, but what many of us do not know is that if your body cannot process the food because of a terminal illness, forcing nutrition in will not prolong life. There is a natural process in the dying: decreased appetite, decreased thirst, gradual withdrawal from the concerns of this world and focus on concerns about death and taking care of "unfinished business" with family.

When the body's metabolism begins to shut down in the dying process, it no longer builds the body's tissues and organs; this is what is called an "anabolic" state of metabolism. When the body's tissues and organs begin to break down, whether or not nutrition is taken in, it is called a "catabolic" state of metabolism. In the catabolic state, food is not absorbed, tissues no longer heal well, infection is difficult to cure and an irreversible downward spiral is set into motion. Whether a patient eats food, is fed a liquid diet through a feeding tube, or gets intravenous nutrition ("total parenteral nutrition" or "TPN"), the nutrients taken in will not stop this catabolic process.

## **Constipation, Comfort & Lack of Appetite**

Knowing when the catabolic state is reached is sometimes difficult to assess and is really a question for the attending physician. However, there can be some very important things to be done which can improve appetite in those who have not reached the catabolic state. In the terminally ill, and especially with those who are taking several medications (especially opioid narcotics for pain), constipation can become a serious and even life-threatening concern.

Constipation is a very common side-effect of narcotic pain medications such as morphine. That is why laxatives are commonly ordered at the same time a narcotic medication is started for pain. Constipation if left untreated can become a total blockage of the digestive tract or an "impaction." The minor discomfort many know as constipation, becomes a severe problem with possible extreme pain, gas, bloating, total lack of appetite, nausea and vomiting.

A complicating factor in determining the cause of the lack of appetite and abdominal pain may be the patient's reluctance to even discuss his or her bowel problems. It can be quite upsetting or embarrassing for some patients to admit to these types of problems. Bowel function is one of the "private" areas of our life which nobody relishes discussing. Some patients feel humiliated by their need to discuss or deal with these problems. Sensitivity on the part of the family and hospice staff can go a long way toward easing the patient's reticence.

Actually knowing how often the patient's bowels are moving and their nature is really important for patient comfort. This is one reason nurses pay a lot of attention to this area. It is not a question of prying into private matters. It is essential information needed by the nurse to accurately assess the patient and act accordingly. The nurse needs to know if the bowels are moving regularly every day, every couple of days or longer. Are they soft or hard? Painful to pass? Is there much straining? What color are they? Does the patient have abdominal pain, gas or bloating? The answers to all of these questions and others tell the nurse and physician much and can help them help you deal with these problems. Many patients hide their problems with their bowels and will not readily discuss these areas. One may be thinking that the patient's lack of appetite signals the "end" when the patient may simply be severely constipated.

So before anyone concludes that a "catabolic" state of metabolism has set in, one has to make sure that there is no constipation or impaction involved. To prevent such complications, hospice standing orders include progressively stronger laxatives and "bowel programs" such as phosphate enemas and if necessary, mineral oil enemas. Hospice nurses are experts at resolving these sorts of problems which can be severely uncomfortable for their patients.

Simply taking a stool softener such as Colace (docusate) is not enough for those patients taking opioid pain medications. Stronger laxatives such as PeriColace (docusate + casanthranol) or Senokot (from Senna) are used in increasing dosages as necessary to keep the bowels moving. If the patient has not been able to prevent constipation from becoming serious, the nurse administers enemas, perhaps more than one day in a row, in order to clear out the blockage. Mineral oil is extremely effective in softening hardened stool in the large intestine and rectum. Because the large intestine cannot reabsorb the oil like it does with water in the bowels, the stool remains softened and can be removed with a simple flushing enema of warm water or phosphate. Patience is necessary, and sometimes, applying an oil enema and then waiting till the next day will allow for easy removal. A patient who has an impaction may find an abrupt approach much too painful for quick removal of hardened stool. The hospice nurse must work with and respect the patient's ability to tolerate the procedure.

It is quite common to find that a patient who had been severely constipated or impacted may regain their appetite, energy level, become more responsive and eat or drink much more than earlier. Adequate medication for bowel management is essential to patient comfort.

## Artificial Methods of Feeding, Tube Feedings and IV Nutrition

Artificial methods of feeding a patient are some of the most controversial interventions available, along with other forms of prolonging or supporting life that would not continue without doing something to assist the patient. Patients who lose consciousness and slip into a coma cannot eat on their own; patients who have severe strokes with consequent injury to their brain function often cannot eat on their own and may have serious swallowing difficulties which make oral feeding "contraindicated" ... the food, if given, may be taken down into their lungs and "aspirated." Anyone who cannot consciously swallow and also "protect their airway" (by making sure the food goes down into their stomach) is at risk for aspirating food into their lungs, causing a type of pneumonia called "aspiration pneumonia." For the terminally ill, adding a case of "aspiration pneumonia" to their difficulties may be the final stroke that takes them from us.

To avoid aspiration pneumonia, some patients or families, with their loved one's permission (hopefully) may request the doctor to place a feeding tube of one sort or another. Liquid nutritional formulas are given through these tubes and the patient is often not allowed to take any food or liquid by mouth/orally, in order to avoid aspirating the food or liquid into the lungs. Tubes that go into the stomach are "gastrostomy tubes" or "G-tubes." Tubes that are placed down the nose into the stomach are called "Nasogastric tubes" or "NG tubes." Tubes that are placed down the nose into the small intestine are called "NJ tubes," because they pass from the nose down into the jejunum, a section of the small intestine.

When the patient has a disease of one or more of the digestive organs which makes it impossible for the patient to digest food, the surgeon may place a central intravenous line ("IV") for the purpose of giving nutrition directly into the blood vessels. A patient who gets all of his or her nutrition through such a central line is getting "total parenteral nutrition" or "TPN" for short.

## Quality of Life Considerations

Placement of feeding tubes into the stomach or small intestine is common in patients who have had a stroke which interferes with swallowing, but who otherwise do not have a terminal illness. They are perceived to have a chance to maintain an acceptable "quality of life" which "justifies" the placement of the artificial feeding tube. In those cases where the patient does have a terminal illness, the patient or family must "wrestle" with the decision of whether or not to place a feeding tube to get nutrition into the patient when the patient cannot swallow on his or her own. Placing a feeding tube into the actively dying patient would normally be considered inappropriate, because the patient cannot absorb the nutrients. A physician would most likely state that he or she could not "justify" placing a feeding tube in that situation.

If the patient has a terminal illness and needs a feeding tube, but would live for a "reasonable" length of time and have a decent quality of life, surgeons will usually agree to place a feeding tube. What constitutes a "reasonable" length of time or what constitutes an "acceptable" quality of life are questions which medical ethicists struggle to answer and which families and patients must answer every day. Many surgeons would refuse to place a feeding tube into the actively dying. Putting the patient through the trouble of the procedure would not bring results which would improve the patient's longevity or quality of life. Some health professionals might consider the placement of a feeding tube at such a time, a form of cruelty.

However you may think about it, some family members argue bitterly over such decisions. That is one important reason for patients to fill out "Advanced Directives" for Medical Care forms in which they clearly delineate their wishes for health care, should they become unable to communicate their wishes on their own. Some family members are unable to "let go" and ask for every possible medical intervention which may prolong the patient's life. Some health professionals may question whether the interventions are being performed for the welfare of the patient or to somehow make the family members feel better, less guilty, or comfortable. Medical social workers are experienced in assisting families work through these types of decisions and should be utilized when family conflicts may interfere with the welfare or wishes of the patient.

Questions which need to be answered are: Is the patient able to "enjoy" the quality of life he or she has? Does the patient wish to prolong his or her life, or is he or she ready to let go and pass on? Is the patient conscious or does the patient have a possibility of regaining consciousness so that later, he or she may have an "acceptable" quality of life? Will the procedure increase or decrease the patient's suffering? Or would it prolong the patient's suffering? What are the patient's own wishes regarding these types of medical interventions?

Hospices do not usually institute measures which artificially prolong life; rather, the hospice approach is to promote patient comfort and quality of life, which may indirectly prolong life, but which certainly increase the patient's "enjoyment" of any remaining time left. Although hospice is aimed at relieving symptoms and promoting patient comfort, a hospice patient always has the legal right to pursue any medical intervention he or she wishes.

Whether or not the insurance, Medicare or Medicaid will pay for such interventions is an important factor to take into consideration and explore. Whether or not a physician will agree to such procedures is another question. If you have these types of questions, it is important to speak with the hospice medical social worker who can provide answers to these questions and thereby assist you in making an informed decision on your own. In some cases, the insurance, Medicare, or Medicaid will pay for certain procedures if the physician can "justify" the procedure from a medical point of view, that it is "reasonable and necessary" for the patient's welfare.

If it is found that the "hospice benefit" will not pay for certain procedures, it may be possible for the patient to "revoke" the hospice "benefit" in order to temporarily qualify for the regular medical coverage under Medicare or other insurance. After a procedure is done, the patient can then return to the hospice benefit by re-"electing" the hospice benefit.<sup>(15)</sup> Although this may sound confusing or complicated, it is the hospice social worker who can help to make the necessary arrangements for the patient's welfare and you should discuss your concerns with your medical social worker.

## **PAIN CONTROL: METHODS AND STANDARDS OF CARE**

Pain control is one of the central goals of hospice care. Most patients and families who use hospice services expect that the hospice will make every effort to relieve the pain which afflicts their loved one. From the legal standpoint, the federal guidelines regulating hospice require the hospice to make every reasonable effort to assure that the patient's pain is controlled. Most state laws governing hospice also make pain control a primary and required component of hospice care.

Using hospice services will, in most cases, assure that the patient receives the pain medications needed to control his pain: the hospice Interdisciplinary Team and the hospice RN case manager are focused on making sure the patient is comfortable. The attending physician who orders all medications should be focused on the same goal, and in many cases does see to it that the patient is kept comfortable. Unfortunately, for varying reasons, some physicians may not order the needed medications to adequately control the patient's pain!

In these cases, the hospice staff must intervene to protect the patient and make sure the patient gets what is needed to control pain. The hospice medical director, being a physician, has the authority to give medical orders and can intervene to provide the patient with the needed medications. In fact, the hospice medical director is required by law to make sure the patient's medical needs are met; these needs include medication for pain.<sup>(16)</sup>

## Medications

In most cases, physicians will begin to treat pain with what are called "over the counter" pain medications such as acetaminophen (Tylenol), ibuprofen (Motrin), aspirin or others. As a terminal disease with pain involvement continues to take its toll, pain levels will likely increase to the point where these over the counter ("OTC") medications no longer help at all. Then, the physician will prescribe other stronger medications. Narcotic medications in combination with other medications or narcotic medications alone are commonly used to relieve pain in the terminally ill.

It is important for the patient to receive the appropriate medication for his or her condition. Different types of pain respond to different medications. If there is bone pain, one type of medication is useful, while if there is abdominal pain from spasms, other medications may be useful. Nerve pain may respond to other medications, or even surgeries for pain management. Giving more narcotic medications is helpful with certain types of pain, while in other cases, it does not "touch" the pain.

It is amazing, in the case of a patient with abdominal spasms, to see a patient's excruciating pain respond to a simple medication made to treat that problem, when a very strong dose of morphine may not provide any relief. Increasing the dose of a medication which is not appropriate does not help, and only increases the adverse side-effects which good medical management tries to avoid.

Hospice nurses work with many physicians and know which of them are adept at treating the many symptoms which arise in a terminal illness. Just as there are better surgeons available for specific operations, there are better nurses and better attending physicians available. Knowing which doctor is of the "better" quality can make all the difference between an unnecessarily terribly painful death and a peaceful and comfortable death. Some of us "choose" a physician by chance, by taking the physician assigned to us in a hospital or a referral, without looking into the physician's "record." Word of mouth references from a trusted friend or relative, about a physician who successfully treated pain in others is one of the best recommendations you can look for.

### No Basis for Fear of Addiction

In the terminally ill patient's case, there is no basis for any fear about "becoming addicted" to a narcotic given for pain. Although many individuals have strong beliefs about avoiding "drugs," meaning illegal drugs such as cocaine, heroin and others, the legal use of narcotic medications for pain is totally appropriate and a welcome relief from the severe pain which plagues certain patients. Addiction is a problem for those who are not dying.

The terminally ill patient who suffers from terrible pain needs these medications to relieve that pain. Using narcotic medications for the terminally ill patient is truly compassionate and humane. It is for this purpose that such narcotic medications exist! Nobody should feel ashamed about taking such medications to ease the pain of a terminal illness, and nobody has the right to deny a patient these medications when they need them. The severity of pain some patients experience is quite mild, while others experience the most excruciating levels of pain. Modern medical science can effectively treat most pain and keep the patient comfortable. If a patient is still painful, the physician needs to be consulted immediately for adjustments or changes of medication, or for other treatments for pain.

### Other Treatments for Pain

There are other things which can be done to reduce the level of pain in your loved one. Anything which causes added tension or stress should be avoided. Those interventions which help the patient to relax are definitely quite helpful. Providing an atmosphere

which is in harmony with his or her wishes is important. This means that those patients who have a natural appreciation for music may be helped with calming, soothing music. There is an entire field of health care now dedicated to "music therapy" and research confirms that music, used properly, can have wonderful benefits for many patients.

For those patients who prefer silence, a quiet atmosphere should be maintained. It is distressing to note that some families argue loudly in front of the patient, apparently not caring enough to avoid disturbing him or her, even when the patient is actively dying. Such arguments certainly disturb the patient and can only add to their tension and pain. Some patients may find massage of some sort helpful, others may simply wish to be held. The simple presence of someone who loves the patient can be extremely soothing and helpful. You can be creative to find what helps and supports your loved one's comfort. For some, a warm bath can help, while in others, the attempt to get into a bath would be too painful to even attempt. If there is any abdominal pain, it is important to make sure there is no constipation or blockage ... which can be extremely painful.

There are also other medical interventions which may be helpful when your loved one experiences severe pain. If narcotic medications, given in sufficient dosages (and that is crucial here) do not relieve the pain, the route of administering the medication may be changed from oral to subcutaneous or to intravenous ... or you may need to consider giving the medication epidurally. There are some physicians who even cut through certain nerves to relieve pain. The subject of pain relief is extremely vast, and if the patient is not getting relief, you need to get a "second opinion" from a physician who is an expert in treating pain in the terminally ill. There are pain treatment centers in many cities. If you are willing to work with your physician, and the physician is willing to work with you, then there is no need for so many patients to suffer needlessly.

## Physical Signs Your Loved One May Be In Pain

Although many patients freely express their pain, it is quite common for some patients to attempt to hide their level of pain, in order to protect the family from feeling bad about the patient's suffering, or to help the patient appear "strong." Some patients believe that suffering is a normal part of life and to avoid pain is "cowardly" or "weak," while others see pain as a "purifying" force which helps them along in their religious path.

While each patient has the right to accept or refuse treatment for pain (or any medical condition), hospice philosophy embraces the idea of relieving pain and bringing comfort to the patient who desires it. Hospice nurses or doctors are not there to "force" pain

medications on patients who do not want it, although it sometimes happens. The family is in a difficult situation when the patient will not or cannot communicate in words what level of pain is occurring.

It is not possible for a patient to totally "hide" his or her pain level. When pain is severe, many physical changes occur which alert the observant hospice nurse or family member about the pain levels. Not all changes occur in all patients, but some will occur in all patients. Systolic blood pressure may increase from the usual level for that patient, heart rate may increase, the rate of breathing may increase, the patient may hold his arms or legs tightly or the rest of the patient's body may be "tight." When the patient is moved or turned in bed, the patient may instinctively "guard" his position to protect certain parts of the body from pressure which would cause increased pain, above what it already is. Even if the patient cannot speak, some moaning may occur. If the patient raises his voice or calls out, it is quite likely that pain is severe.

Each one of these factors taken together can give the experienced hospice nurse a very accurate "picture" of the patient's level of pain. When medications have been ineffective to relieve the patient's pain, the nurse must contact the physician for medication orders to increase the dosage or change the medication (according to the physician's judgment). It is important for the family to attempt to get clear and unambiguous communication from the patient about his or her pain level. If this is not possible, then the physical signs of pain need to be closely evaluated.

### Physicians Who Refuse to Order Adequate Pain Medication

It is likely that in any major city or metropolitan area, there are some physicians who simply do not follow the standard protocol for treating pain. It is unlikely that they are totally unaware of the standards for treating pain, especially if they've been in medical practice for several years or more. The United States Department of Health and Human Services, Public Health Department has convened conferences of experts on pain management in cancer and other diseases. Standard procedures for pain management have been clearly delineated for any physician to follow, and these standards are safe and effective for pain management.

You might be surprised to learn that there are physicians who refuse to take calls about their patients' pain levels or who ignore nurse's and family pleas for pain medication. Any physician who refuses to receive phone calls about a terminally ill patient's pain level or who consistently does not intervene as necessary to relieve the patient's pain should be

immediately removed from the case! Why should a patient keep a physician who does not provide the service for which the physician was hired??? In the meantime, you can definitely request to speak directly with the hospice medical director who is legally authorized (and obligated actually) to step in and order the needed medications for the patient's pain relief.

Be sure, the medical director can step in and order what is needed, even if it might "offend" the attending physician to have someone challenge his or her medical orders or judgment. If the medical director hesitates to step in and take over when the attending physician refuses to provide adequate care, explain that you know that the medical director has legal authority to do so and is actually obligated by federal law to do so. If the medical director still refuses to step in, and the patient continues in pain, either change attending physicians or get a different hospice completely! You can choose hospices, and one hospice may be much more helpful than another in this situation. You can even have the hospice's own medical director act as the attending physician if you cannot find another physician to take over.

If the patient is unable to communicate this wish on his or her own, then the family must step in and get another physician. In this case, hopefully, the patient has filled out a "Durable Medical Power of Attorney" so that another person can legally make these decisions for the patient. The hospice is required to allow you to change physicians, and nobody has the right to tell you that you cannot change physicians, at any time.

The hospice must maintain continuity of care, even if you change attending physicians! The terminally ill need physicians who are dedicated to the hospice philosophy of compassionate care and are willing and able to order the needed medications for pain, so that your loved one is kept as comfortable as possible. Many patients needlessly suffer excruciating pain, simply because the physician has decided not to order what is needed by the patient!

# PHYSICIANS AND NARCOTIC MEDICATIONS FOR PAIN

## Some Patients Under-Medicated for Pain

There can be no doubt that the use of narcotic medications for pain is well-accepted in the medical community. Such medications have been used successfully to control pain and keep a patient comfortable. However, it is well-known that certain patients have died in extreme pain, even when some pain medications were given. The question remains: "why?" "Why should any patient suffer extreme pain when medical science has the tools to relieve pain effectively?"

While medical science, in general, has the "tools" to relieve most painful situations, it is certain that some physicians are more expert than others in the application of those tools to the relief of pain. In other words, there is an "art" to medical skill as well as the "science" of medicine. There are many reasons why a physician may not order the administration of adequate pain medications.

## Physicians Are Individuals With Their Own Beliefs About Pain

Hospice nurses are advocates for their patients. They call physicians on a regular basis to request changes in medical orders to relieve their patient's pain. It is no secret among hospice nurses that certain physicians routinely refuse to order adequate medications. The comments heard from these physicians vary, but are infuriating and often insensitive in the extreme. Certain physicians personally believe that "pain is part of dying," "there is virtue in suffering," "it is not the physician's role to relieve pain," and "if a person has a terminal illness, pain is a necessary component of the dying process."

No hospice will tell you that there are physicians in your own community who routinely, always fail to provide the needed pain medications to keep your loved one comfortable! It is disgraceful that many terminally ill patients die in severe pain needlessly, and, that the hospices fail to intervene in many cases, to assure that the needed pain medications are given. While it is safe to say that most hospice nurses almost always call the physician for orders for the patient's pain, it is also safe to say that many hospice nurses' request for adequate pain medications are ignored by certain physicians who routinely refuse to

prescribe what is necessary. In these cases, the hospice medical director is legally required to intervene to make sure that the patient's pain is properly relieved.

If you have a physician who under medicates his patients for pain, you most likely have no way of knowing that, unless you have heard from other patients who had pain and were treated by that particular physician. The hospice nurses may lose their job if they tell you their honest opinion about the physician you have. You need to be extremely sensitive to "hear" what a nurse may be trying to tell you about a physician's orders. (Some physicians may not like to hear this, but it is the fact ... nurses are advocates for their patients, and the physicians should also be, but are not always what the patient wants, needs and is entitled to.)

### Hospices Are Businesses Which Compete for Patients & for The Money Generated By "Getting a Patient" Enrolled in the Hospice

Why would a hospice fail to intervene when the physician refuses to prescribe the needed medications for pain??? The obvious answer to this question is the same as what is wrong with most of the health care system: health care agencies often violate standards of care in order to save money or to bolster their financial status. While you may not look upon your loved one as a "source of revenue," hospices and other health care agencies do see patients as a "source of revenue."

No hospice will tell you that it is a business, with a bottom line, and the hospice may not always do what is right for your loved one! Of course there are many hospices that will do what is right for your loved one. The problem is that some hospices do not do the right thing! Payments are made to the agencies for services billed, and bills can only be submitted if there are patients in whose name the bills are made out.

Physicians are referral sources for patients; patients are sources of revenue, therefore, hospices must not "offend" the physicians who are referring the patients. Why? Because there are other hospices, and the physician can choose to refer his patients to another hospice or to a home health care agency and to no longer refer to that hospice. Hospices compete with one another for patients, and some of them prefer to "please" the physician rather than advocate for the patient and "step on the toes" of the physician.

While it may seem inconceivable that hospices may ignore the needs of the dying for pain relief, but that is the reality ... the well-kept secret scandal. It also may seem inconceivable that one doctor is so important to a hospice, as a referral source for dying

patients. It must be remembered that most physicians work within "group practices" which may be quite large, numbering from two or three physicians up to ten or more physicians. If one physician is so offended by a hospice "challenging" his or her medical judgment about the needs of the patient, he or she may choose to no longer send any patients to the hospice, and even more significant, the physicians' group practice can jointly decide to send their patients elsewhere. Physician groups can "make" or "break" a hospice's dominance of the "hospice market" in your community! Hospice administrators know this and have instructed their staff to not offend the physicians. Sometimes hospices choose to accept inadequate orders for pain medications, though they know the physician routinely under-medicates!

### Some Physicians Are Ignorant About the Proper Use of Pain Medications

It is well-known that medicine now is so specialized that no one individual can be expert in all areas of the practice of medicine. Specialties in hospice or "palliative" medicine are especially useful for the effective management of your loved one's pain. Specialties in "pain management" is also especially useful for the effective management of your loved one's pain. Many of those physicians who have specialized training in "palliative" medicine are often hospice medical directors. Physicians with specialization in pain management are often employed in "pain management clinics" within acute-care hospital settings. Your doctor may not have this specialized training! You need to question your physician about his or her philosophy of treating pain. Not having the specialized training available, some physicians "do not know" the effective use of certain medications for pain management. "Not knowing" is not a "sin," but if the physician fails to provide needed medication, because he doesn't know, that is a disgrace. It is a violation of your loved one's rights if the physician fails to provide the needed medications and fails to seek advice if he doesn't know how to properly relieve your loved one's severe pain.

You need to consult with the hospice medical director or another physician who knows how to care for the dying in pain, and who is willing to order the needed medications. Do not wait too long before insisting on speaking with the medical director of the Hospice. If you do not get satisfaction there, then contact other physicians who may be willing to take the case and order the needed pain medications.

### Physicians May Fear Prosecution for Prescribing Narcotics

While it may be incomprehensible to you, some physicians do not order adequate pain medications because they believe, falsely, that they will be prosecuted by the government for over-prescribing narcotics to the terminally ill. It is necessary for physicians and

nurses to adequately document the patient's pain in the medical chart, however, many physicians who order adequate narcotic medications for pain are never questioned by the government or medical authorities. Some physicians' fear threats of lawsuits from a patient's own family. A family member which might allege that the physician over-medicated the patient and therefore the patient died, when in actuality, the patient died simply because of the terminal illness.

Many people do not understand the use of narcotic medications for pain, do not understand the symptoms which arise as a part of a terminal illness, and do not understand that the illness itself may be the cause of the patient's death. There are symptoms such as lethargy, non-responsiveness and confusion which are part of the dying process, which may be confused with side-effects of the narcotic medications used for pain. If the patient is actively dying and also receiving pain medications, some family member may blame the physician for the patient's death, wrongly.

### Some Physicians Routinely Over-Medicate Their Terminally-Ill Patients

While some physicians do not provide their patients with enough medication to control their pain, other physicians are so aggressive in their treatment of the terminally ill that they knowingly "push" their patients over the edge to death, even though the patient is not ready to die, not willing to die at that time, and simply asking for adequate pain relief. Physicians may "help" a patient to die more quickly than he or she would naturally do, when the patient is willing to die or unwilling to die. Different opinions about voluntary assisted suicide have been raging across the country.

Dr. Kevorkian of Michigan is one example of a physician who believes in the practice of "euthanasia" or "assisted suicide." Dr. Kevorkian's point seems to be that people should have the right to die, by unnatural means, whenever they wish to do so. He has assisted many persons in dying, by providing the mechanisms and medications for them to die. Whatever your point of view about assisted suicide and euthanasia, hospice (meaning the hospice philosophy and the hospice's proper role) is not in the business of performing "assisted suicide" at all. Hospice is about helping the patient and family to be comfortable, relieving symptoms, and respecting the patient's and family's wishes.

However, over-medicating a patient, against his or her will, does happen. Over-medicating a patient, with the patient's consent, also does happen! You, as the family/care giver, need to be alert and watchful to see that your loved one's wishes are honored, and that pain is controlled. There is a very fine line which needs to be reached where the

patient is comfortable, yet adverse side-effects are avoided. Some physicians do act as if they believe they have the right to make decisions for the patient about the patient's care. Doctors are not licensed to make the patient's own decisions for them! Doctors are not God! Hospice nurses must advocate for the patient's own wishes, and the physician is required by the standards of care to act in accordance with the patient's own wishes.

No hospice will tell you about the doctors who have over-medicated patients' pain, in the mistaken belief that a patient in pain is better off dead, than suffering yet alive. The sad fact is that some physicians have pushed their patients over the edge, but these physicians are in the minority. Most physicians are quite sensitive to the needs of the patient and work as hard as they can to help the patient remain comfortable. We must condemn the actions of those physicians who violate their patient's wishes, but we must also clearly state that there are many physicians who are greatly dedicated servants of the public.

### Some Physicians Fear the Adverse Side-Effects of Narcotic Medications

Narcotic medications, like all medications, may have serious side-effects, in some patients, in some circumstances. Serious side-effects from narcotics can be avoided by skilled and knowledgeable physicians. Yet, even common over-the-counter medications can have serious side-effects. With narcotic medications, the common side-effects are more serious than over-the-counter medications. This is the reason that narcotics are considered "controlled substances" which have special legal controls about their distribution and availability to the community. Because of the possible serious side-effects from narcotic medications, it is important that you make sure to get an attending physician who is knowledgeable about the use of narcotics, hospice and helping the terminally ill.

"Respiratory depression" is a major side effect of narcotics. In respiratory depression, the patient's breathing becomes slower, with a weaker breathing effort, and if the "respiratory depression" is extreme, the patient's breathing could actually stop. The cessation of breathing may be for very short periods of time, after which the patient again begins to breathe, called "apnea." On the other hand, breathing could stop permanently, resulting in the patient's death. How does a physician know how much medication to order? There are standard protocols or accepted standards of practice which guide a physician in the prescribing of narcotic medications. There are standard methods for increasing or adjusting the dosage of medications, and for changing from one narcotic medication to another.

When a physician follows the standard protocol for adjusting the pain medication, respiratory depression is rarely experienced. Your hospice nurse and your attending physician can explain the protocol for adjusting the medication if you have questions about respiratory depression. In addition, if the patient's breathing becomes too slow, the dosage is usually reduced or even held completely, until the patient gets used to the medication.

Lethargy or profound sleepiness may be a common side-effect of narcotics. If the patient is still taking liquids, it may be helpful for the patient to have "caffeine-containing" drinks such as coffee or black tea. These drinks are stimulants which can help the patient become more alert. Of course, you must consult your hospice nurse and physician about what should be done in your particular case, if the patient is too lethargic. It may be that other medications are making the patient sleepy, but it could be that the patient is actually "pre-actively dying" or "actively dying." If your loved one is "pre-actively dying" or "actively dying," the lethargy is likely simply a natural part of the dying process. Many patients begin to sleep more as they come closer to actually dying.

Constipation is a common side-effect of narcotic medications. When constipation occurs in the terminally ill patient, it can cause abdominal pain which is unrelated to the pain resulting from the disease. Some cases of constipation can progress into a full-blown blockage of the intestinal tract, or "impaction." Impaction of the large intestine is a medical emergency and can result in death. It must be carefully managed and treated to remove the blockage, if the patient is not already at the point of death. If the patient is not actively dying, your attending physician will order medications or treatments to relieve the constipation or impaction. Your hospice nurse will administer enemas to relieve the impaction; mineral oil based enemas can soften the material blocking the intestine and with subsequent enemas, the blockage can be removed. Hospice nurses are expert in managing the side-effects which occur in the terminally ill, and especially in conjunction with the use of narcotic medications.

Nausea and Vomiting may be a common side-effect of narcotic medications. When a patient suffers from a terminal illness, he or she may have nausea and vomiting as a result of the disease. On the other hand, medications themselves may cause nausea and vomiting. If the patient has severe pain, the physician may have no choice but to order narcotic medications for pain relief. If the patient then experiences nausea and vomiting, the physician will normally order a medication to control or suppress the nausea and vomiting ... an "anti-emetic" medication. These medications can be quite effective, but must be given regularly as needed to keep the nausea and vomiting from returning.

You will need to always be aware of what medications your loved one is taking, and whether or not your loved one's symptoms are a sign he or she is close to dying, or a side-

effect of a medication. Review of the medications being given should consider what common side-effects those medications have and whether or not the medications are causing those symptoms. Sometimes a change of medication can relieve the patient's symptoms. For example, one narcotic may be less likely to cause nausea and vomiting, or one anti-emetic may be more effective than another. Certain laxatives may be more effective than others. Changes in medication are common in care for the terminally ill and should be expected. They are part of providing appropriate and sensitive care for the dying.

## **PROLONGING LIFE IN THE ACTIVELY DYING**

While hospice is concerned with comforting the dying and not actively prolonging a patient's life by treating a disease, it is sometimes desirable to try to put off a patient's death for a little while ... and it can be done. You may have never heard about such a possibility and may ask why would a terminally ill person, who's at the very end, want to hang on any longer. On the other hand, many of you would want to extend life at any point.

### **Unfinished Business**

Dying is about finishing up the "unfinished business" of one's life and preparing for what is to come. Family members may need to express long held back feelings. Time is sometimes so short that family members may not have had time to even travel to be at their loved one's side. If family members live in different States or even countries, distance becomes a great obstacle to family members who wish to be at the bedside at the time of death. It is not always easy to predict the exact moment when a person will actually die. However, there are signs that an experienced hospice physician or nurse will look for. It is possible, in general, to know when the patient is in the "active phase" of dying, with only a few days left of life. If the family is unable to arrive immediately, the approach of death creates problems in "getting there" on time.

When a patient receives a terminal diagnosis, they may have only a few days left, a few months, or longer. If there are only a few days left, family start to travel from all directions. If the patient becomes unresponsive and the blood pressure is dropping, family may not be able to reach the bedside on time to say "goodbye." In the acute care hospital, when blood pressure drops too low, the physicians order medications ("vasopressors") which increase the blood pressure back to the normal range. When a patient has a terminal illness and is dying, the physician will not order these medications to prolong a patient's life. The patient's comfort becomes the focus of medical care, and when death occurs is not an issue for the physician. However, it is an issue for the patient and the family.

Many medications (given to the terminally ill for pain or terminal agitation) actually lower the patient's blood pressure as a side-effect. Although these side-effects are not desired, the medications are necessary to control the pain or agitation and help keep the patient comfortable. When the patient has not been taking in fluids for days, or has been taking in such small amounts that dehydration is setting in, the blood pressure drops lower and lower as a natural part of the dying process. However, the patient and family always have the right to take whatever food or drink they wish, as long as the patient is capable ... and, some drinks have effects on the blood pressure in a manner similar to "vasopressors" given in the hospital ... they increase blood pressure.

The other action taken in hospitals to save patients whose blood pressure is dropping dangerously low, is to give fluids. You have probably heard of emergency room physicians ordering Intravenous fluids ("IV") immediately ("Stat") for patients who are losing blood and whose blood pressure has dropped dangerously low. Getting fluid into a dying patient may cause serious problems and discomfort if the patient cannot handle more fluid. For example, the lungs may be filling up with fluid and giving more fluid can make the problem much worse. But in the case where the lungs are not filling up with fluid, giving extra fluid by mouth or feeding tube can bring the blood pressure back up long enough for the patient to say "goodbye." It is important to be able to "let go" of the patient when the patient is really ready to pass on, and prolonging the life of a dying patient who is ready to go, is not ethical. Death is a natural part of the life cycle. However, there are exceptions when a few hours longer will make all the difference.

Some families who knew that their loved one was actively dying and knew that a relative was traveling from afar, have given strong coffee to the patient in order to bring the blood pressure back up a little. Some patients' blood pressure increased by 30 or 40 points (or mm on the blood pressure scale). If the patient is unable to drink, some families have given a few drops of coffee at a time by medicine dropper or "oral syringe" into the mouth and let it be absorbed directly in the mouth ("sublingual"). Strongly brewed coffee given regularly every few minutes or so, in drops or by feeding tube, in some cases, can bring the blood pressure up, counteract the effect of blood pressure lowering side-effects

of some narcotics and help the patient live long enough to say "goodbye" to a family member. In those circumstances where a few hours or one day can make all the difference, some families have found coffee to be of great help.

## **QUALITY OF LIFE AND QUANTITY OF LIFE ARE *not* THE SAME**

It is natural for all of us to wish to live as long as possible. We might think that nobody ever wants life to end, or that we could ever want our lives to end. However, as our life situation changes, our ability to enjoy life may decline. At some point, as we come closer to death, health declines, energy declines, involvement in the world around us declines and in many cases, unpleasant experiences such as pain, helplessness and mental or physical deterioration increase. It is one thing to gleefully enjoy life when one's energy level is high and all one's faculties are fully intact. It is quite another thing to enjoy life even when in extreme pain, unable to physically do anything, and physically or mentally deteriorating. Watching our loved one in such a condition is perhaps the most difficult experience of all!

How many of us would wish to live long lives if we could not enjoy the "pleasures" of life, could not contribute to society or our families, could not "give back" to others, but could only receive assistance and care from others? It is easy to "talk," but it is more meaningful to walk in another's shoes for one hour or one day, than to "philosophize" about what you would do if you were in the same situation. Many people become "ready to die" when their health fails seriously and they can no longer participate in the activities they once loved. Very elderly persons may complain about pain, loss of vision, food no longer appealing to them, loss of energy and depression.

How we navigate the challenges of life and how we change to accommodate those changes which come to all of us, depends to a great extent upon our philosophy of life, our beliefs about the purpose and meaning of life and the religious views we hold or do not hold. Even if we live long lives, there often comes a point where there is a "readiness" to die. Why? Because life no longer appears fulfilling or meaningful, or for those who believe in a spiritual life beyond death, because of a hoped for entrance into heaven and reunion with loved ones.

Sure, if we could have the health we had when we were younger," or "if we could return to the days when our friends and loved ones were still alive," or "if things were different," ... .then maybe we'd reconsider. But we do not always get to choose what happens to us or our loved ones. Life happens to us. In some situations, we make some choices which may affect our health, but in many instances, diseases attack our bodies for no apparent reason. Perhaps environmental pollutants cause cancer, or we are exposed to a fatal disease through no fault of our own, or genetically we are predisposed to a certain disease. There is not much we can do to change these tragedies, even though medical science may be researching how to conquer these diseases and even prevent them from occurring at all.

Some of you may find it hard to understand why anyone might wish to "let go," even when a terminally ill disease strikes. You may believe that "life is sacred." Yet there is a saying that there is a time to be born and a time to die; it is simply a part of life which must be accepted, sooner or later, for everyone. Even if life is sacred, death is also sacred, and everyone has their own appointed time of death, their own destiny. The process of death can be horribly painful, full of grief and sorrow ... or it can be inspiring, peaceful and accepted in an atmosphere of great love. That may be incomprehensible to some, but many hospice nurses do their work, because of it; to honor and respect the living while they are with us, and to allow the dying dignity, peace and comfort.

Certainly, a part of us wishes to deny death its inevitability, to fight and never surrender. "Fighting the good fight" is admirable and worth attempting. Eventually though, death comes to all, and this is not necessarily a defeat or "depressing." It simply is the truth. Extending life when a person's will to live is lacking does not make sense. Even though the "will to live" is the strongest instinct we have, those of us who have sat at the side of numerous dying patients know that there comes a time when a person is convinced that it is their time to go. And even though not all dying persons accept death willingly, even at the very end, most do accept it and make peace with its inevitability.

## Declining Level of Consciousness

When a person's level of consciousness is severely compromised, the quality of life issue becomes even more pronounced. What is "level of consciousness?" It is how aware one is of one's surroundings, how alert one is, how responsive one is ... . If a person responds to questions, sound or touch in a meaningful way, we can conclude that they are alert and aware, especially if they can still speak to us or open their eyes and move them to follow us as we move around them. As death approaches, the level of consciousness often (but not always) declines so that the person no longer responds in any way. First, the person

may become very sleepy, and then actually fall into a sleep from which they may be aroused, and eventually, they may sleep and not be arousable. Even if presented with loud speech or strong touch or movements, a person who is "asleep" at this deep level will not respond; this is what is called a "coma."

Within the realm of unresponsiveness in persons who are asleep, there are variations as well. One person may have inner awareness, but be unable to respond, talk or indicate in any way that they are aware of what is going on around them. Others may be unaware of their surroundings and quite "unconscious." In other cases where severe brain damage has occurred, there may be no possibility of conscious awareness of their surroundings ... the level of consciousness is not there at all.

When level of consciousness declines, most people feel and think that the "quality of life" has declined with it. Under those circumstances, there are intense debates about the meaning of continuing to live and whether or not it is desirable. This is where numerous points of view arise and we cannot generalize and state with certainty what anyone would want. The standards of care in our health care industry require us to respect the individual patient's wishes and not to impose our own.

Modern medical science is capable of keeping the body "alive" with artificial respiration and heart bypass machines, but merely keeping the cells of the body alive when there is no consciousness, no brain function is not "life" as we know it. When the quality of life has declined beyond any meaningful point, many choose to let go and not take any measures to treat life-threatening changes; they refrain from efforts to resuscitate the patient and do not put the patient on artificial life-support such as a ventilator for artificial breathing and heart bypass machine for artificial circulation of the blood; they accept death knowing that the time has come. Hospice care is about improving the quality of life as much as possible, but it does not take action to artificially prolong life in most situations.

## **RESPIRATORY DISTRESS AND OXYGEN**

Patients with terminal illnesses may experience respiratory distress, difficulty breathing comfortably. Shortness of breath may be mild or extreme. Persons who have diseases affecting the lungs or heart disease are especially likely to have shortness of breath. One of the simplest things one can do to help relieve shortness of breath is to help the patient to sit up. If you have a hospital bed, the head of the bed is made to raise up. If the patient has refused a hospital bed, you can still elevate the head of the bed by placing a large

cushion or two (from a couch or pillows) evenly under one end of the mattress to elevate your loved one's head, neck and trunk. A 30 or 45 degree angle of elevation should be sufficient. This is especially important for any patient with heart or lung disease.

The next basic thing you can do is to give concentrated oxygen to the patient. The attending physician will ordinarily order oxygen for any patient who has shortness of breath, or the hospice RN case manager may arrange for oxygen based on physician-approved standing orders for hospice care.

### Fluid Buildup in the Lungs

In certain cases of heart failure and lung disease, there is a high probability of fluid building up in the lungs. Medical science has found that the fluids building up in the lungs can be minimized by aggressively administering certain medications (such as scopolamine, hyoscyamine, atropine, and other medications, and in some cases, morphine). Morphine in combination with a diuretic such as furosemide (Lasix) may be very effective when pulmonary edema is present. If there is any fluid accumulating in the lungs, the physician may order these or other medications to remove that extra fluid (See the section on - Fluid Management in Terminal Illnesses, for more information). If the patient's lungs are quite "wet" and the patient is unable to swallow, you may wish to inquire about giving the medications transdermally (by applying medicated patches to the skin) or subcutaneously (using an injectable form of medication with very small needles which are not painful to use).

### Administration of Oxygen

Oxygen is most commonly given by nasal cannula which is a plastic tubing that reaches to the nostrils. It is also given by a mask which covers the mouth and nose. In both cases, the nasal cannula or mask are attached to plastic tubing which attaches to a source of oxygen: oxygen tanks of various sorts or oxygen concentrators.

Oxygen is given at a certain speed or rate which is measured in liters per minute. A 2 liter per minute rate is quite common in adults, although when there is severe shortness of breath, the rate is increased to 3, 4 or 5 liters/minute in some cases. It is very important to follow the physician's orders about how much oxygen to given per minute. In the

endstage of a disease such as Chronic Obstructive Pulmonary Disease (COPD) or emphysema, suddenly increasing the oxygen to a high rate of flow could cause worsening respiratory distress or even respiratory failure, hastening death. If the patient is having difficulty, consult with your hospice RN case manager who can, if necessary, call the physician for further medical orders regarding the oxygen or other medications which might be helpful.

### Care Needed When Using Pure Oxygen

When oxygen is given, it is extremely important not to smoke in the same area or building at all. Smoking, besides being extremely harmful to the patient, can accidentally cause a fire. It is important not to have any flames or candles in the room. Oxygen accelerates the combustion rate and a fire could result. There are some patients who either ignored this caution or were confused, and accidentally started to smoke when they had oxygen coming in by nasal cannula; some of these patients were burnt severely and in some cases a fire was started in the building!

If you have oxygen tanks in the room, it is important to prevent them from falling abruptly. The oxygen is under great pressure within the tank and the tanks can either explode or shoot across the room, Serious injury could result if the oxygen tanks are mishandled. If the tanks are properly stored and used, there should not be any problems. The Medical Equipment Supplier who brings the tanks will teach you how to use the tanks safely.

### Oxygen is an Important Comfort Measure for the Patient

Providing oxygen to your loved one will help keep him or her comfortable and reduce the shortness of breath. When patients become short of breath, anxiety can be dramatically increased which makes the problem even worse. If you notice that your loved one is short of breath and no oxygen is yet being provided, ask the RN case manager to obtain oxygen as soon as possible. In many hospices, the RN case manager can use the standing orders already approved by the attending physician to get oxygen into the home as soon as the medical supply company can bring it out.

If you are told that oxygen is not necessary, even though the patient is obviously short of breath, determine exactly why the RN doesn't think your loved one needs oxygen. If you personally know a nurse in your area, ask her to come over for a second opinion. If both of you still think the patient needs oxygen and the RN is balking at ordering oxygen, demand to speak with the hospice medical director or contact your Attending physician directly. Insist that your loved one gets the services needed to maintain comfort! If the attending physician himself also refuses to order oxygen, you may wish to contact another physician. There have been reports of kickbacks to physicians who save money on the care provided to patients by not ordering the needed services (like oxygen) or medications. This is the same type of "cost-saving" that sometimes occurs in HMO's or other insurance plans ... it benefits the agency but does nothing but make the patient suffer more.

### Altered Patterns of Breathing

It is quite common for the terminally ill to exhibit altered patterns of breathing. What this means is that the patient may breathe abnormally slowly, quickly, may pause for short or very long periods (called apnea), or may breathe in irregular patterns or rhythms of breathing. Each pattern or rhythm of irregular breathing has a specific cause, meaning and interpretation which experienced hospice physicians and nurses will recognize.

Although you may find it difficult to see your loved one breathing in these ways, it may be a sign that he or she is in decline and getting closer to death, or that certain organs are failing. Longer and longer periods of apnea (pausing when breathing) can occur, lasting from five to ten seconds or even up to one minute or more. After these periods of apnea, breathing again resumes and the pattern may repeat itself. These periods may get longer as your loved one approaches closer to passing away, but this does not happen in all cases. Some patients may breathe extremely fast up to thirty or forty breaths per minute or more. These altered patterns are to be expected and do not necessarily mean that the patient is suffering due to that pattern. Sometimes these altered patterns of breathing continue for weeks or even months. It is important that you report any changes in breathing pattern to your RN case manager who can explain their significance to you.

## **RESPIRATORY FAILURE AND VENTILATORS**

When patients can no longer breathe on their own, there is an option of using a ventilator to keep the patient breathing. In hospice care, the emphasis is on maintaining patient comfort but not on attempting to cure a terminal illness. In many cases, a patient stops breathing when many organs within the body fail due to disease. This is normally the time of death, but in some cases, a patient may choose to be kept alive on a ventilator.

In certain diseases, the patient is fully aware and conscious, but the muscles used for breathing no longer function properly. Diseases of the nervous system such as A.L.S. (Lou Gehrig's Disease) can eventually cause total inability to move any part of the body, even the muscles of breathing. Some A.L.S. patients choose to be placed on a ventilator in order to stay alive.

Certainly, the decision to use a ventilator is a difficult one to make. Quality of life is severely compromised by certain diseases, yet some choose to extend their lives through the use of a ventilator. If a patient dependent upon a ventilator is not likely to die within six months, then he or she would not be hospice appropriate and would be better served by home health care staff or a facility.

## **SEDATION, PAIN CONTROL AND QUALITY OF LIFE**

### **Sedation Sometimes Necessary for Pain Relief**

Hospice care is an art as well as a science, just like any aspect of medical and nursing care. When patients are in severe pain due to a terminal disease, the strong medications required to keep them comfortable may have sedative-like effects, placing the patient into sleepy states of awareness, especially in the case of the elderly who cannot metabolize the medication as well as others, or during the first few days patients start to take the medication. While it is possible for some patients to receive extremely high doses of narcotics and remain fully alert, awake and comfortable, some patients are only able to achieve full relief from pain with dosages that make them sleep.

## Patient May Prefer Alertness over Pain Relief

The ideal goal in hospice care normally is to keep the patient as comfortable as possible. In those cases where the patient experiences strong sedative effects of the medications, some patients will accept sleep and comfort as a welcome relief from their suffering. However, in certain other situations the patient may place more value on remaining totally alert and awake till the very end. The quality of life issue becomes a choice between pain relief and remaining awake and able to communicate with others or be aware of who is there, what is going on and still participate consciously in life.

Those patients who prefer to remain as alert and awake as possible may sometimes refuse narcotic medications, and of course, the hospice and family should respect the patient's wishes. Some patients may refuse pain medications in the belief that pain is a necessary part of death, or that being stoic and not complaining is important. These are all personal decisions for each patient, and families may have other ideas about what should be done. This can be extremely difficult and heartbreaking for family, friends and hospice to handle. We prefer to do our best to relieve the pain our loved ones may be experiencing.

## Physicians' Practice in Relieving Pain

Physicians vary widely in how they treat pain in the terminally ill. This may be surprising to those who are not well-experienced in dealing with physicians. Some physicians will provide all the relief from pain that medical science can offer. Others refuse to prescribe strong narcotics in dosages which are sufficient to relieve the pain. Hospice philosophy believes in relieving the pain, and condemns those physicians who choose to abandon their patient to his or her suffering without trying their best to relieve that pain.

Some physicians believe in ordering gradually increasing dosages of pain medications until a sufficiently strong and effective dosage is reached. This well-tried and trusted approach, when used in combination with anti-anxiety or sedative medications, can be a very effective combination which helps the patient achieve the highest level of pain control and still remain as calm and alert as possible.

Still other physicians may go overboard in treating the pain of the terminally ill ... they believe they are "God" and decide to put the patient out of his misery, putting the patient "to sleep" permanently. Those physicians who unilaterally choose to overdose their patients are as much to blame as those physicians who under medicate their patients' pain. What should be clearly understood by all patients and families is that there are definite standards of practice about how to treat pain, how to increase dosages, what medications to use, when to begin new medications (if previous medications have been ineffective) and so on.

Medical science is very capable of relieving pain in the terminally ill. It is sometimes the unwillingness of the physician (to provide medications which are effective in dosages sufficient to relieve the pain) which is the real reason so many dying patients' pain is unrelieved. In so many cases suffering is unnecessary.

Death does not have to be painful. Good hospice care under the direction of a competent physician who knows how to treat pain will effectively relieve the pain in most patients. Sometimes palliative use of chemotherapy or radiation may be necessary. Sometimes surgery may be needed for pain relief. Sometimes one or more medications knowledgeably administered will be all that is necessary to relieve the pain. Relieving pain is crucial to your loved one's quality of life! The most important factor in achieving pain control is having the right physician who is willing and able to order the treatments or medications necessary to bring comfort to your loved one. If pain is relieved, the dying process can be a peaceful, calm transition with family members expressing their love and support throughout.

## **UNDERSTANDING STANDING ORDERS IN HOSPICE**

Hospices function differently from what you might be used to when visiting a physician's office, clinic or hospital. When your loved one enters a hospice program, the physician has certified them to be eligible for "the hospice benefit." The hospice benefit includes all services, supplies and equipment needed by the patient for care related to his or her terminal illness. The physician agrees to supervise or direct the care that is provided, in collaboration with the entire hospice team. The case management of your loved one's care is mainly handled by the RN assigned to you. This RN case manager has authority to start medications in certain very specific situations in order to treat these certain problems that routinely arise in caring for the terminally ill.

Each hospice has a list of routine medications or treatments which may be begun (ordered) without contacting the physician beforehand. This list of medications or procedures is called the list of standing orders. Hospice patients experience many common problems and symptoms which are treated in routine ways. Because the symptoms are so common, and the medications used to treat these symptoms are used over and over again, the RN case manager is able to recognize which medications fit the conditions specified in the hospice standing orders and which your physician has approved. If your physician did not approve standing orders, he would notify the hospice, and the standing orders would be modified according to the physician's discretion.

The use of standing orders allows the hospice nurses to intervene immediately when symptoms arise and helps to assure quality hospice care for your loved one. It also frees up the physician to see patients in the normal course of his or her medical practice without literally hundreds of calls each day for routine medical orders which he has already specified in the standing orders.

Even though the standing order medications are begun by the licensed nurses caring for your loved one, the physician is notified in writing that these medications have been started. In the case of strong narcotic medications, the laws governing pharmacology require that the physician actually give the order to start these legally controlled medications. There are certain exceptions in emergency situations, however, the physician will certainly be notified before any narcotic is released from a pharmacy.

What is important to understand about hospice and standing orders is the idea that care for your loved one is managed by the hospice Interdisciplinary Team. The physician is not normally called day after day for routine orders. Many of the orders are started by standing order and written notification is sent to the physician for his or her signature. The physician is not involved so much on a daily basis, unless he or she chooses to remain that involved. In the situation where the standing orders do not address the specific problem which is occurring, the licensed nurse will call the physician for specific orders. The nurse will also call and consult with the physician for new orders if the medications prescribed by standing order are not effective.

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## **TIPS ON BEDSIDE CARE**

There are many challenges to come in caring for your loved one. Mobilizing all the assistance you can get will be very important in helping you provide the very best care possible. There will be times when it will be difficult for you to get an opportunity to sleep, when important decisions will need to be made, when you will be physically, emotionally and mentally exhausted. Learning how to care for your loved one without straining is important. To help you care for your loved one, the following topics will be discussed below:

- Making Arrangements for Assistance
- Scheduling Helpers
- Positioning the Bed
- Raising & Lowering the Ends of the Bed
- Siderails and Safety
- Terminal Agitation
- Using a Regular Bed
- Keep Linens Flat & Smooth
- Need to Reposition Patient Up in Bed
- Need to Avoid Dragging
- Drawsheets Used to Lift or Turn
- Turning Your Loved One
- Changing the Sheets
- Dealing with Urinary Incontinence
- Dealing with Bowel Incontinence
- After Death Care

#### Making arrangements for Assistance

If you have friends or family members who are willing to help out, you could make out a list of people willing to help out around-the-clock, for when it becomes necessary. Of course, because of the intimate nature of bedside care, any person helping would have to be acceptable to your loved one. A friend or relative who is a nurse would be able to demonstrate how to provide bedside care. The RN case manager from the hospice will also show you what needs to be done. When a person is unable to get up out of bed, or even turn in bed by themselves, they are dependent on the caregiver for their needs. Hospice care is directed toward meeting the needs of the terminally ill. You will be an important part of the overall team that helps to keep your loved one comfortable and helps to meet his or her needs.

#### Scheduling Helpers

Being organized in making schedules for help will help relieve you of bearing the full responsibility for care. Even with hospice services, there will be many times when you will need to be at the bedside assisting your loved one. Of course, if there is an actual

crisis of out of control symptoms, then the hospice will provide additional Continuous Nursing Care. Learning how to provide the care needed (without straining your back or otherwise injuring yourself) is so important.

The hospice's RN case manager assigned to you will be most helpful in providing you with the information you need to provide care for your loved one. You will be able to pick up many helpful insights into bedside care by observing the hospice nursing staff when they are in your home. You can ask them to show you how to care for your loved one.

### Positioning the Bed

Because you will be caring for your loved one when he becomes unable to move or turn on his own, the bed must be positioned so that you can walk along both sides of the bed and reach him from either side. Trying to work from only one side is not practical, may cause you to strain your back, and will make bedside care extremely difficult.

### Raising or Lowering the Ends of the Bed

It is helpful to have a hospital bed for patient care for when a patient's strength declines and they are unable to get up on their own. Hospital beds have mechanisms to raise or lower both the head or foot of the bed, which makes patient comfort easier to maintain. It is common for many patients to resist the idea of using a hospital bed, feeling that allowing a hospital bed into the home is equivalent to admitting defeat, that death is approaching. However, the reality is that death is approaching, and patient comfort is the goal now. When patients have congestive heart failure or respiratory disease, a hospital bed's ability to raise the head of the bed will greatly help the patient to breathe easier.

### Siderails and Safety

Hospital beds also have siderails which can help prevent the patient from falling out of bed. They serve to physically hold the patient back in bed if they roll over onto their side and also remind the patient about the edge of the bed. These are extremely important to have if the patient is confused or may become confused. It may be necessary to have someone sitting with your loved one 24 hours a day if he or she becomes seriously confused or agitated. When a patient is very confused, she may attempt to get up out of bed independently, even though she's too weak to stand on her own and would fall down.

### Terminal Agitation

Many patients (although not all) may become quite restless or even agitated as they approach nearer to death. Even if your loved one is normally quite calm and peaceful, how he acts at this time may change dramatically and drastically. Some patients become quite anxious and seemingly nothing you do can help them calm down. This type of agitation is called terminal restlessness and is a major symptom which needs to be controlled for your loved one's safety and well-being. Experienced hospice nurses know that such a patient, if left alone for even a moment, may get up out of bed and fall or injure himself. Some patients have been known to crawl over or in between the siderails of a hospital bed, and then fall! The attending physician will order medications which will help to calm your loved one down and relieve the agitation.

### Using a Regular Bed

If your loved one refuses to use a hospital bed, it is possible to place cushions (such as might be used in couches) under the mattress to raise the head of the bed up and help the patient breathe more comfortably. Placing pillows on top of the bed is not as effective or easy to use. Siderails may be purchased at some department stores which can be secured in place by placing a part under the mattress.

### Keep Linens Flat and Smooth

Keeping the bottom bed sheets flat and smooth will help your loved one to be comfortable. Wrinkles in the bed or any debris will irritate the skin and cause discomfort as well as injury to the skin. While it is not easy to completely straighten out the linens when the patient is in the bed, you can snug up the sheets on one side, roll the patient on top of the smooth sheets, and then smooth out the other side. Also remember to leave the top sheet loose enough so that it does not press down on his feet or feel uncomfortable. Some patients become so sensitive that they cannot tolerate anything at all laying on top of their feet, even a sheet!

### Need to Reposition Patient Up in Bed

As your loved one weakens, he will be unable to reposition himself in bed for comfort. Even though unable to reposition themselves, many patients tend to move down toward the foot of the bed over time, requiring regular assistance to get back up toward the head of the bed. If assistance is not provided, the patient remains slumped down too far toward the foot of the bed and will not only feel uncomfortable, the position can interfere with ease in breathing and also cause unnecessary pressure on the base of the spine (coccyx) and result in skin breakdown.

### Need to Avoid Dragging

When your loved one experiences difficulty turning himself or pulling himself up in bed, pulling or pushing him without lifting will result in dragging his body across the bed. Dragging him from side to side or up in bed can cause injury to the skin, so it should be avoided. Any time you wish to turn or move him, the bed should be flat, if possible. If you have a hospital bed, the electric or manual controls will allow you to lower the head of bed briefly while this task is performed.

### Drawsheets used to lift or turn your loved one

When moving a patient in bed, it is quite useful to place folded sheets across the bed linens with your loved one on top. Then when it becomes necessary to help move your loved one, you and another person can pull and lift this draw sheet to turn or move him in bed. This helps to avoid dragging him across the bed. Pulling on the patient's arms to position him should be avoided. The sheet should be folded so that the distance from the shoulders to the knees is lifted when using the draw sheet. How to use a draw sheet is something your nurse can demonstrate for you.

### Turning from Side to Side

In hospitals, it is the standard to turn or roll a patient in bed every two hours, so that skin breakdown and bedsores do not occur. If your loved one is unable to move on his own, you will need to turn him on a regular basis. Using a drawsheet is helpful for turning as well as pulling your loved one up in bed. Your RN case manager will be able to advise you as to how often turning is necessary in your situation.

When you assist your loved one to lay on his side in bed, you can use a rolled blanket or a pillow tucked against his back to help keep him on his side, otherwise he may roll back over onto his back. Placing a pillow between the knees and ankles can help make your loved one more comfortable as well.

In some cases, at the very end, it will not be appropriate to turn your loved one in bed, because this could be more disturbing or painful at this time. There is no need to be concerned about bedsores if the patient is actively dying. Maintaining comfort is most important. Whatever is done should be based upon your loved one's comfort.

## Changing the Sheets

When your loved one becomes bedbound and cannot reposition himself, it will be more difficult to change the sheets. But changing the sheets on a regular basis is important and can help him to be more comfortable; keeping clean and dry are part of patient comfort. The way to change sheets with the patient in bed is to get the patient to turn and move toward one half of the bed, then pull the sheets out on one side and tuck them under the patient, place clean sheets on the unoccupied side of the bed with the excess tucked against the patient, roll the patient back onto the clean sheets and pull out the old sheets, then pull the clean sheets all the way out and make the bed, tucking the ends under the mattress. With a little patience and nursing technique, the job can be done without too much difficulty!

## Dealing With Urinary Incontinence

Part of the transition from this life to the next is a decreasing focus on the concerns of this world. All terminally ill persons will eventually lose control of their bladder, either at the actual point of death or before, because of disease or loss of consciousness. This can be extremely depressing and humiliating to your loved one. Maintaining privacy for your loved one is extremely important when providing intimate care.

Before a patient becomes totally incontinent, a bedpan may be offered for a female who cannot get up to the bathroom or a bedside commode, and a urinal may be placed for a male. Making sure the bedpan or urinal is available on a regular basis is very effective in maintaining continence when your loved one is still conscious and able to void at will. You should offer the bedpan or urinal regularly so that he or she doesn't need to ask you for it in front of others. Telling visitors that you need a little privacy for a few moments is perfectly acceptable and preferable to letting your loved one be incontinent because a bedpan or urinal was not available soon enough to be used. Taking charge in order to ensure privacy is acceptable to everyone.

If incontinence of urine is occurring on a regular basis, you will need to place incontinent pads underneath your loved one. These can be reusable and washable (made of cloth) or disposable. You will also need to place incontinent briefs to absorb urine and help keep the skin dry. These will need to be changed every few hours as needed, after washing.

Changing of incontinent briefs can be done by:

- turning the patient on his side,
- tucking the visible portion of the brief under him,
- washing up that area exposed,
- tucking a folded half of a new brief next to the old one and laying out the other half under the patient, then turning the patient back onto the other side,
- pulling the old brief out along with the new one and washing the area exposed and then securing the new brief in place.

Skin that becomes irritated or reddened should be cleansed, patted dry (not rubbed) with a soft towel, and a moisture barrier may be applied. Your RN case manager will explain how to deal with irritated skin.

### Dealing with Bowel Incontinence

While bowel incontinence may be a result of loss of consciousness or disease, it may be a result of loose bowel movements or diarrhea caused by side-effects from medications or other causes. It is important to make sure the RN case manager is closely monitoring all medications being given to make sure they are properly adjusted. Laxatives can be overused in some cases and must be closely evaluated. Offering the bedpan on a regular basis can help avoid incontinence if your loved one is able to control this function at this time.

As in the case of urinary incontinence, incontinent pads and briefs will need to be placed to prevent soiling of the bed and to help keep the patient clean and dry (please wear disposable rubber or vinyl gloves). After removing any bowel movement with toilet paper, a wet soft cloth or disposable wet wipe should be used to remove any remaining soiling and to assure complete cleanliness. If there is stool in pubic hair, an effective way of cleaning up is to apply shaving cream and then wipe with soft damp cloths.

Some patients may be so embarrassed and humiliated by bowel incontinence that they refuse to eat, drink or take any laxatives necessary to avoid constipation related to pain medications. In these cases, constipation may become so severe that the patient suffers from extreme abdominal pain, cramping and bowel obstruction, which is, in itself, a life-threatening condition. For this reason, it is important to communicate your love and understanding for your loved one, maintaining privacy, providing adequate time for bowel functions, and to listen to your loved one's concerns.

### After death care

For many family members, even thinking about death or after death issues is virtually impossible, ... something to be avoided at any cost. However, your loved one may have definite wishes about the funeral, after death care and other arrangements. Different religions have certain restrictions about after death care which must be respected. It is important to find out if your loved one has specific requests about after death care and arrangements.

After death occurs, the hospice nurse will either assist you with after death care or perform this care by herself. Your loved one's body may need cleansing due to urinary

and bowel incontinence. Clothing may need to be changed if soiled. The body should be placed in a suitable position for viewing, with legs straight and head of bed lowered down flat. If rings or other jewelry are to be given to others after death occurs, they should be removed after family and close friends have an opportunity to say goodbye.

Depending on the religious beliefs and wishes of your loved one, the minister, priest, rabbi or shaman may be called to perform prayers with the family present. In other religious traditions, no special prayer is performed after death, but is to be performed before death occurs. All of these issues need to be addressed long before death occurs.

It is quite common for families and close friends to wish to visit at the scene of death right after death occurs. It is a very intimate time for final goodbyes to be said. This is one reason why it is so important to allow all family members and close friends this opportunity to say goodbye.

The hospice nurse, chaplain or social worker may assist you in calling the funeral home and will remain with you until the funeral home leaves with the body. It is your decision to have or not have a hospice representative with you at this time. When the representative from the funeral home comes out to the home, he will ask for the exact time of death, name of the attending physician, date of birth, and other information. If a hospice representative has remained with you, he can answer the questions asked by the funeral home staff. It is helpful to make decisions about funeral arrangements prior to the time of death if at all possible, because after death it is an extremely emotional time, and making such decisions at that time can cause even more emotional upset. It is also helpful to make decisions prior to death, because your loved one would have an opportunity to express his wishes.

## HELPING YOUR LOVED ONE IN & OUT OF BED

### Transfers from Bed to Chair

In many cases there will most likely be times when the patient will wish to get up out of bed. It may not be advisable for him to get up in some cases. If there is a realistic danger that your loved one will fall, he should not get up alone, and must be assisted by enough people to assure his or her safety.

There are times when some hospice patients will repeatedly request to get up out of bed, and then once in a chair, will soon thereafter request to get back in bed ... repeatedly requesting to get in and out of bed. In this case, the patient may be suffering from what is called terminal agitation/restlessness. This problem can become exhausting to you, and

the hospice RN case manager and physician must be notified. There are several medications commonly used to relieve this terminal agitation or restlessness.

When a patient is suffering from various symptoms or pain, moving can make things worse. If your physician has ordered pain medications to be given on an as-needed basis, it is good to administer pain medications at least one-half to one hour before attempting to move him. Listen closely to your hospice RN case manager for tips on managing pain before transfers.

You may find that your loved one will suffer from dizziness after laying down for prolonged periods. If you have two persons helping out, one person can lower the patient's legs over the edge of the bed while the other simultaneously helps him to sit up on the edge of the bed, supporting him at the shoulders. This technique for sitting up is simple to accomplish once you have watched professional nurses demonstrate. After waiting for him to recover from any dizziness, the transfer to a chair can be attempted.

Depending on the patient's strength, the distance to the chair should be adjusted. If the patient is able to support his weight and stand, a little walk to the chair is good exercise, as long as someone is assisting him, supporting him by the arm to steady him if necessary. If however, he is weaker, the chair should be placed next to the bed without any space in between; you may wish to use a transfer or gait belt which is applied around the patient's waist, secured and which can be held to support the patient's weight during the transfer. Watching this being demonstrated is helpful.

When your loved one is feeling quite weak, it is important to prevent falls and any injury that might result. Watch how the hospice nurses assist your loved one. You will notice that the nurse assisting him will place her feet and knees directly in front of your loved one's feet and knees, blocking them in place, preventing his legs from sliding out from under him. Proper lifting technique will help you avoid injuring yourself as well. Using the legs to lift, positioning your loved one as close as possible to the chair, using a gait/transfer belt to help him up, all of these techniques are helpful.

#### Assisting Your Loved One Back to Bed

If your loved one has already fallen, then it is important not to strain while helping him back to the chair or bed. Get help when lifting him back up. If you have any doubt about your own ability to assist him back up, getting assistance from other family members, neighbors or friends is appropriate. If there is nobody around who can assist you, you may call the hospice for assistance. In some cases, the hospice will advise you to call your non-emergency local police telephone number or EMS/ambulance for assistance. Straining yourself in the process will only make things more difficult for all involved.

A useful method of lifting is for two helpers to join in lifting simultaneously, grasping each other's wrists under the patient's hips with one arm and grasping each other's wrists behind the patient's back and under his arms ( sometimes called a fireman's carrying technique). Another method is to take a strong blanket and spread that out on the floor next to your loved one, and position him on the blanket ... then using two to four helpers, lift the patient by lifting the blanket up like a stretcher. It is important to have enough people assisting depending on the weight of your loved one. Ask your RN case manager to demonstrate methods for assisting your loved one in and out of bed or from the floor.

### Assisting to Bathroom

If you need to assist him to the bathroom, the transfer or gait belt can be used as well as using a walker or cane, if the patient is strong enough to use them. Your loved one's ability to walk may become unreliable, and you will need to carefully evaluate his ability as you begin. If there is any indication he's unable to safely transfer, then the attempt to get up should be stopped immediately. Your hospice RN case manager will be able to give you guidance.

If the patient is unable to walk to the bathroom, then a portable commode may be placed next to the bed for his use, or a wheel chair can be used. Privacy must be maintained. There is nothing more humiliating to your loved one than sitting on the bedside commode while visitors are present. It is appropriate to ask others to step into another room during use of the bedside commode or bathing. If the patient's bed is not in a private bedroom, a sheet may be hung across the room for visual privacy as well.

## MAINTAINING A PEACEFUL ATMOSPHERE

### Sound and music

What type of environment will be conducive to peaceful rest for your loved one will depend on his or her preferences. Many patients enjoy listening to restful, beautiful music which helps them relax, while some are used to the TV or radio blaring at all hours. Others will prefer silence. What is important is to be sensitive to the patient's wishes and keep things the way he or she prefers.

## Lighting

While a few patients will appreciate opening all the curtains and letting the scenery in from outside, many others will be bothered by the bright lights from outside. Some will want windows open, others may be disturbed by drafts and ask for windows to be closed. All of these factors are important. Especially important is to avoid loud arguments in front of or within your loved one's hearing. It is rare that a patient is not able to hear loud arguments, and even if the patient appears to be in a coma (sleeping soundly) you cannot be sure they do not hear you. In most cases, hospice nurses assume that the patient can hear you. There have been many instances where patients later informed family that they did hear discussions or arguments. Even at the very end when the patient is actively dying and unable to move, many patients are able to hear very well.

## Limit the number of visitors

It is important for you to limit the number of visitors according to not only the wishes of your loved one, but his or her strength as well. Many well-wishers may come by and your loved one may not really have enough energy to entertain them. After a few visits, your loved one may simply wish to sleep, but will exert himself to be polite to others and stay awake. This can have an adverse affect on his health, causing fatigue, tension and even increase pain levels.

## Control visiting times

It is helpful to post a sign on the outside door to your home, advising visitors of specific times when visitors would not be interfering with bedside care or sleep. You will have to determine how much your loved one can handle. The amount of time may vary from day to day and as time passes. The actual amount of time you allow visitors into your home must be controlled, and at some point in time, you will become the gatekeeper. Your loved one is vulnerable and will not always be able to speak for himself. There is a fine balance to be reached somewhere between allowing too many visitors and isolating your loved one from his friends. This will not always be easy, because the dying process is not simply a physical decline, it is a transition in which communicating with others is a vital process. Saying goodbye, finishing unfinished business, typing up loose ends ... . Hopefully, healing wounded relationships and expressing mutual love.

# **SIGNS AND SYMPTOMS OF APPROACHING DEATH**

Without a doubt, questions regarding the signs of approaching death are the most common. However, there are many ways of determining that death actually is very close.

When confronted with approaching death, many of us wonder when exactly will death occur. Many of us ask the question, "How much time is left?" Unless death is actually imminent, this can often be a difficult question to answer. The dying do not always cooperate with the predictions of the doctors, nurses or others who tell family members or patients how much time is left.

Hospice staff have frequently observed that even the predictions by physicians about the length of time from the original diagnosis till death is often inaccurate. Many families report that "the doctor told us he [the patient] only had so much time left, and he's lived much longer than that." ... or a similar story. Statistical averages do not tell us exactly how long a particular patient has to live; they can only serve as a general guideline or point of reference.

Although statistical averages do not help much in an individual case, there are specific signs of approaching death which may be observed, and which do indicate that death is approaching nearer. Each individual patient is different. Not all individuals will show all of these signs, nor are all of the signs of approaching death always present in every case.

Depending on the type of terminal illness and the metabolic condition of the patient, different signs and symptoms arise. An experienced physician or hospice nurse can often explain the meaning of these signs and symptoms to you. If you have questions about changes in your loved one's condition, ask your hospice nurse for an explanation.

There are two phases which arise prior to the actual time of death: the "pre-active phase of dying," and the "active phase of dying." On average, the pre-active phase of dying may last approximately two weeks, while on average, the active phase of dying lasts about three days.

We say "on average" because there are often exceptions to the rule. Some patients have exhibited signs of the pre-active phase of dying for a month or longer, while some patients exhibit signs of the active phase of dying for two weeks. Many hospice staff have been fooled into thinking that death was about to occur, when the patient had unusually low blood pressure or longer periods of pausing in the breathing rhythm. However, some patients with these symptoms can suddenly recover and live a week, a month or even longer. Low blood pressure alone or long periods of pausing in the breathing (apnea) are

not reliable indicators of imminent death in all cases. God alone knows for sure when death will occur.

### **Signs of the preactive phase of dying:**

- increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently (exhausting family and caregivers)
- withdrawal from active participation in social activities
- increased periods of sleep, lethargy
- decreased intake of food and liquids
- beginning to show periods of pausing in the breathing (apnea) whether awake or sleeping
- patient reports seeing persons who had already died
- patient states that he or she is dying
- patient requests family visit to settle "unfinished business" and tie up "loose ends"
- inability to heal or recover from wounds or infections
- increased swelling (edema) of either the extremities or the entire body

### **Signs of the Active Phase of Dying**

- inability to arouse patient at all (coma) or, ability to only arouse patient with great effort but patient quickly returns to severely unresponsive state (semi-coma)
- severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality
- much longer periods of pausing in the breathing (apnea)
- dramatic changes in the breathing pattern including apnea, but also including very rapid breathing or cyclic changes in the patterns of breathing (such as slow progressing to very fast and then slow again, or shallow progressing to very deep breathing while also changing rate of breathing to very fast and then slow)
- other very abnormal breathing patterns
- severely increased respiratory congestion or fluid buildup in lungs
- inability to swallow any fluids at all (not taking any food by mouth voluntarily as well)
- patient states that he or she is going to die
- patient breathing through wide open mouth continuously and no longer can speak even if awake
- urinary or bowel incontinence in a patient who was not incontinent before
- marked decrease in urine output and darkening color of urine or very abnormal colors (such as red or brown)
- blood pressure dropping dramatically *from patient's normal* blood pressure range (more than a 20 or 30 point drop)

- systolic blood pressure below 70, diastolic blood pressure below 50
- patient's extremities (such as hands, arms, feet and legs) feel very cold to touch
- patient complains that his or her legs/feet are numb and cannot be felt at all
- cyanosis, or a bluish or purple coloring to the patients arms and legs, especially the feet and hands)
- patient's body is held in rigid unchanging position
- jaw drop; the patient's jaw is no longer held straight and may drop to the side their head is lying towards

Although all patients do not show all of these signs, many of these signs will be seen in some patients. The reason for the tradition of keeping a vigil when someone is dying is that we really don't know exactly when death will occur until it is obviously happening. If you wish to "be there" with your loved one when death occurs, keeping a vigil at the bedside is part of the process.

Always remember that your loved one can often hear you even up till the very end, even though he or she cannot respond by speaking. Your loving presence at the bedside can be a great expression of your love for your loved one and help him to feel calmer and more at peace at the time of death.

If you have questions about any of the changing signs or symptoms appearing in your loved one, ask your hospice nurse to explain them to you.

## **DANGERS OF LEAVING MEDICATIONS OUT**

When physicians order medications to control your loved one's symptoms, the hospice assumes the responsibility of making sure that those medications are administered according to the physician's orders. Any medication must be given according to the "Five Rights" of drug administration:

- The right patient
- The right drug or medication
- The right dose (amount) of medication
- The right route of administration (for example, by mouth, injection, intravenously, etc.)
- The right time (according to the frequency ordered by the physician)

If any one of these rules is violated, then serious injury or death could occur. Over-dosages can cause fatal malfunctions of the heart, breathing or brain. Some medications at overly high dosages can cause damage to the liver or kidneys. All of these considerations are foremost in the mind of the physician who is writing the orders. Safety of the patient is a basic consideration in medical care.

In hospice, the patient's comfort is a prime concern. For this reason, narcotic medications are often ordered to control severe pain encountered in many terminal conditions. Narcotic medications when given to the hospice patient in appropriate dosages are not dangerous. The hospice nurse is responsible to teach the patient and family how the medication is to be given. This includes understanding the five "rights" of medication administration: who gets the medication, which medication, how much to give, how to give the medication, and when to give the medication.

A common initial side-effect of opioid narcotic medications is slowing of the breathing. When a physician first orders the narcotic medication, the hospice nurse must carefully watch to observe how the patient responds to the medication. Is the pain controlled? Are there any serious side-effects occurring? Is the patient's rate of breathing in a safe range? Breathing for an adult should normally be 12 to 20 per minute, but this can vary widely according to the patient's disease condition and age. A terminally ill patient may have very abnormal breathing rates even without any narcotic medication. The rate may be very fast or slow.

However, less than 8 breaths per minute can be dangerously slow. If the patient is already actively dying and near death, then slow breathing in some cases (but not all) is to be expected. If the patient is not at the point of death, abnormally slow breathing may not be expected and may be sign of an adverse effect from a narcotic medication. It depends on the patient's disease process.

If the breathing becomes too slow when first administering a narcotic medication, the hospice nurse will usually notify the physician, temporarily stop giving the medication and ask the physician for appropriate medical orders to adjust the dosage.

Sedation or "sleepiness" is another side-effect commonly occurring when narcotics are first given to the patient. Sedation can cause the patient to simply be a little sleepy, but it can also cause unresponsiveness, coma or even death if the dosage is much higher than that which is necessary to relieve pain. A dose of narcotic that is not enough to control pain will normally not cause any undue sedation. The appropriate dosage of narcotic needed to control pain will also normally not cause any undue sedation. That is why the physician's orders must be followed. Only a physician can make medical orders to change

the dosage of a medication. In many cases, the physician has approved a "protocol" for increasing the dosage when pain is still not relieved. But the hospice nurse must still contact the physician to obtain new orders when changing a dosage again, beyond what the physician had already approved.

This may be difficult for some to understand, but the hospice nurse will explain these special kinds of physician orders to you. The physician may order a specific dosage which cannot be changed without contacting him or her. On the other hand, the physician may order that the narcotic can be "titrated" or adjusted according to the approved protocol, a predetermined way of adjusting the dosage. Sometimes the dosage is increased by 25% or even 50% after a specified period of time.

But what happens if the wrong person takes the medication? What happens if a person who is perfectly healthy takes a narcotic medication like Morphine, Dilaudid, Fentanyl (Duragesic Patch), or others? Many people have no idea how powerful these medications are! We have received reports of children or teenagers actually dying when they wrongly took narcotic medications (intended for a hospice patient) and "experimented" to see how they would feel, and if they would get "high." Unfortunately, in one case, a teenager found out too late that an overdose of narcotics is nothing to play around with, and paid for it with his life!

If you have narcotic medications in the home for your loved one's comfort, you must maintain "control" of them so that no other person can use them or take them either by mistake or even intentionally. That is why these narcotics are legally labelled "controlled" substances. When the pharmacy dispenses a narcotic, they must have a written prescription signed by the physician in order to release the narcotics to the patient. The nurse or other hospice professional must also carefully record exactly how much medication was given and when, and if there were any adverse side-effects noticed. If the hospice nurse is aware that a drug addict or alcoholic may be visiting the home, then a plan of action must be put into place which will prevent that person from getting to these narcotics!

The dangers of drug abuse are very real for any person who takes a medication which is not ordered for them. Suicides can occur. Accidental deaths can occur. And current drug addicts or alcoholics might be tempted to try these narcotic medications because someone forgot to lock them up and left them out in the open.

If you can reasonably expect any children, strangers, current or former drug addicts or alcoholics to visit, you cannot leave these medications out at the bedside or on a counter anywhere in sight! They must be kept out of reach of children and others who could be injured or die by taking these medications.

Be safe when narcotics are in the home. There are some hospice nurses and families who are haunted by the memory that they did not keep these medications out of reach, and that a child had to die because of that mistake. All narcotic medications and other medications must be disposed of after the hospice patient's death. The medications cannot be left at the home for an unknown amount of time trusting that the family will dispose of them; the hospice nurse must make sure that all the medications are accounted for and properly taken care of according to the disposal policy of the hospice!

The U.S. Code of Federal Regulations 42 CFR 418.96 states:

Sec. 418.96 Condition of participation--Medical supplies.

Medical supplies and appliances including drugs and biologicals, must be provided as needed for the palliation and management of the terminal illness and related conditions. (a) Standard: Administration. All drugs and biologicals must be administered in accordance with accepted standards of practice. (b) Standard: Controlled drugs in the patient's home. The hospice must have a policy for the disposal of controlled drugs maintained in the patient's home when those drugs are no longer needed by the patient. (c) Standard: Administration of drugs and biologicals. Drugs and biologicals are administered only by the following individuals: (1) A licensed nurse or physician. (2) An employee who has completed a State-approved training program in medication administration. (3) The patient if his or her attending physician has approved. (4) Any other individual in accordance with applicable State and local laws. The persons, and each drug and biological they are authorized to administer, must be specified in the patient's plan of care. [from 42 USC 418.96].

The dangers of having narcotics in the home need not be unmanageable. Working together with your hospice nurses, you can create a plan of action which maintains the safety of your home, while still allowing your loved one to get his or her pain medications.

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# **UNDERSTANDING & GIVING MEDICATIONS TO YOUR LOVED ONE**

## **Need for Doctor's Order for Medications**

All medications given must be approved by the attending physician. No other medication or treatment should be given to your loved one without notifying the hospice RN case manager. This is important so that all efforts to maintain patient comfort can be coordinated by the RN. Any medications started by the nurse by use of standing orders have already been approved by the attending physician for specific situations, and the physician will be notified of any standing order medications begun.

## **Ways of Giving Medications**

Medications are taken in different ways or routes of administration. The different ways are chosen by the physician according to which manner will be most effective. During the course of your loved one's illness, the methods will change. Swallowing pills may be the easiest way to take medicine in the beginning, but after some time, it is possible that swallowing will become difficult or impossible.

## **Problems with absorption and Ways of Giving Medications**

Another reason for changing routes of administration are problems with absorption. For example, if your loved one has a disease affecting the digestive system, the oral route may not be ideal. If the liver is affected, medications may not be properly metabolized or processed from the digestive system, interfering with absorption. If the circulation is affected, injections may not be effective in the legs or arms, but may be effective given intravenously. If the patient is having much fluid buildup in the lungs due to lung or heart disease, it may not be appropriate to give medications by mouth, or even sublingually by drops. These are only some of the considerations the physician and RN case manager will be monitoring when thinking about the medications being given.

## Common Abbreviations Used in Doctor's Orders

If you will be responsible for giving medications or treatments to your loved one, the hospice RN case manager will instruct you on which medications the physician has ordered, when and how to give them. There may be a medical chart or sheet for recording when medications are given. In order to help you understand some of the more common abbreviations used on these medication sheets, the following abbreviations are shown here. (Please check with your health care provider for explanations of the abbreviations used by your health care provider/hospice's medical records.)

Abbreviation	Meaning
ac	before meals
pc	after meals
BID	twice a day
q	every
q AM	every morning
q PM	every evening
qh	every hour
qid	four times a day
qd	once a day
tid	three times a day
hs	at bedtime
INH	by inhalation
NPO	nothing by mouth
PO	orally by mouth and swallowed (per os or PO),
SL	sublingual, by drops under the tongue
PGT	per gastric tube, given through feeding tubes
PNG	per NasoGastric or NG tube
PNJ	per NasoJejeunum or NJ tube
PR	rectally
prn	as needed
top	topically (lotions)
TRANS	transdermally, absorbed through the skin, i.e. patches, ointments
SC	injected by needle into the fatty layer under the skin (subcutaneous or SubQ)
IM	intramuscularly, injected by needle into the muscle
IV	intravenous, infused into the veins
gtts	drops can be instilled into the eye, ear or nose

If the physician has ordered medications to be given by injection, by use of a patch or suppository, or by any other means, the hospice nursing staff will explain and demonstrate to you how to give these medications. If you have any questions or difficulties, the hospice will have a nurse available by phone to answer questions. If needed, another on-call nurse must be available to come out and assist you with difficulties.

### Crushing Medications & Giving Medications Under the Tongue

There may come a time when your loved one will be unable to swallow pills. If this occurs, the physician must be notified and asked for guidance. The physician may order pills to be crushed and given with applesauce if your loved one can swallow that mixture. If that is not possible, pills that are crushed can be mixed with very small amounts of water, let dissolve and then given by drops with a dropper or oral syringe. Certain medications available in table or capsule form may not be able to be crushed or opened to be given in this way. In those cases, the physician may order another comparable medication that can be crushed, or he may order a different form of the same medication, perhaps a liquid form or injectable form.

Your RN case manager will explain the physician's orders and how to crush the medications. Two spoons can be used to crush a pill in between them, a mortar and pestle may be used, or you can purchase a pill crusher at your local pharmacy. The drops may sometimes be placed in the area inside the mouth against the cheek or under the tongue depending upon the instructions of your physician. Giving medications by drop under the tongue encourages the medication to be absorbed directly within the mouth and not through the digestive system.

### Dealing With Drying of the Mouth

As death approaches, many persons begin to breathe mainly through their mouth. The mouth is left open at all times and begins to dry out, which can be quite uncomfortable. Some family members apply a small amount of olive oil (or other vegetable oil) with a cotton tip applicator to the tongue and lips, which can help your loved one to be more

comfortable. Applying Vaseline or mineral oil is not recommended for the inside of the mouth.

Although many people attempt to moisten their loved one's mouth with water, there comes a time when he will be unable to swallow, and providing water will cause coughing and choking. For this reason, the olive oil may be preferable. There are also forms of artificial saliva which may be ordered by the physician to deal with this problem.

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## **FAMILY WORKSHEETS**

### **QUESTIONS ABOUT HOSPICE CARE**

While each patient and family situation is unique, there are many questions which each family and patient will have to answer. Questions about the type of care to be provided, the location of the care, who will provide the care, will hospice services be used, what services will be accessed, and so on. Denying the approach of death does not put it off, but it does cause added grief when important questions are left unanswered and turmoil results. Honestly recognizing the approach of death, whenever it may come, allows everyone involved to be better prepared for its actual arrival. Please take the time to think about these questions, discuss the issues openly among yourselves and ask questions from those health care professionals you may speak with, especially your attending physician. You may wish to use these questions as starting points for open discussion with your physician.

#### **THE ILLNESS**

1. What is the nature of the terminal illness diagnosed by the attending physician? Specifically, what are the symptoms of this disease and realistically what symptoms will your loved one be likely to experience?

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2. In the physician's opinion, what objective signs or subjective symptoms indicate that the patient may actually pass away within six months or less, (as required by the laws governing accessibility to hospice care)?

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#### THE PLAN OF ACTION & PERSONAL WISHES

3. Have you openly discussed your loved one's wishes about end-of-life care? If not, why not? And if you find it difficult to do so, have you spoken with your physician, RN case manager or a social worker about your concerns?

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4. Does he or she want to be resuscitated? If not, is a Do-Not-Resuscitate Form Filled Out? (If so, does the physician and hospice have a copy?)

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5. Does he have specific wishes about how care should be provided when his health declines? If he can no longer communicate his wishes, who is legally authorized to make decisions on his behalf? If that person is unavailable, who is the next person authorized to make decisions for him? ... i.e., has he filled out a Medical Durable Power of Attorney Form?

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6. For purposes other than medical issues, has anyone been given a Power of Attorney to act on behalf of or sign for the patient if he is unable to do so? (For checks, bank transactions, and other legal decisions). Has a written and valid Last Will and Testament been made out, clearly specifying your loved one's wishes regarding the disposition of his or her estate? Do you and other family members have a copy of the Will?

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## STAYING HOME

7. Is it important for your loved one to stay at home with family till the very end? If so, how many people in your family or friends are realistically going to be there to help with caring for him when the need arises?

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8. Whatever number of potential care givers you have available, is it enough to cover your loved one's needs for care ... 24 hours in a day, for days or several weeks?

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9. Do you know any health care professionals as friends or in your family who can offer their professional insight and advice, if necessary, to help you understand certain situations which might arise? Are they willing to actually help provide bedside care?

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10. Are you going to use a hospice to help your loved one at home? If so, have you spoken with all the hospices in your area to compare services? Do you know anyone who has had hospice services in your area, and, if so, what do they have to say about the different hospices?

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11. If your loved one is determined to stay at home till the very end, will the hospice send out nurses as needed to help keep your loved one home? If not, will another hospice promise to do so? What will you do if the hospice doesn't send out the nurses needed to keep your loved one at home?

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12. Are children going to be visiting in the home, and if so, how are you going to store medications so that potentially dangerous medications are kept out of their hands? Do you have a locked cabinet for medication storage or is there an inaccessible area where medications may safely be kept? Do you know the telephone number for your local poison control center? If not, have you contacted your local hospital to find out the local telephone number?

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13. If strong narcotic medications or sedatives may be used for symptom control, are there any friends or family members who have a problem with substance abuse and are or have been known to over indulge in alcohol or use illegal drugs? Will you have in place an effective method to prevent these individuals from getting to the patient's medications and taking them secretly?

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14. Do you have an area in the home where privacy can be maintained while bedside care is being provided? If not, can you screen off an area to maintain privacy?

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15. Is there agreement among the family members about how care is to be provided? Are there any important disagreements among the family members about care to be given or not given?

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#### HOSPICE SERVICES

16. Are you aware of all the services which hospices are required to provide for your loved one and your family?

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17. Are you aware that all services needed to meet your loved one's needs and the family's needs are required to be provided on a 24-hour basis, 7 days per week?

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18. Are you aware that hospice services are governed by federal and state laws which specify uniform standards of care for hospice which all licensed hospices must meet?

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19. Are you aware that hospices must inform you **VERBALLY** as well as in writing, of all services which you may be entitled to receive? In other words, they must tell you about all services which they are required to provide.

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20. Have you spoken with friends, relatives or acquaintances who may have used some of the hospices in your area? Does the hospice you are considering using actually provide all services you are entitled to receive?

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21. Have you read any literature about hospice services? Have you read all the literature handed out by the hospice? Have you read all contracts and papers which the hospice required you to sign before enrolling your loved one in the hospice?

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## THE PHYSICIAN

22. Is your loved one's attending physician someone who you have known for a lengthy period? Do you know any families who've had this physician directing end-of-life care for their loved one?

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23. Is this physician experienced in caring for the dying?

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24. How does this physician communicate with you and your loved one? At office visits, do you have an opportunity to ask questions and are your questions answered adequately? What has the physician told you about your loved one's current status and future prognosis?

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25. Has this physician respected your loved one's wishes regarding medical decisions to be made? Have you felt imposed upon?

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26. What Medical Board certification does this physician have? How much experience does this physician have in providing medical care for the terminally ill?

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27. Are you satisfied with the services this physician and office staff have provided to you up to this time? When you have called to ask questions, have you been able to get the physician's responses in a timely manner, or have you had to repeatedly call in order to get a response?

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28. If you are dissatisfied with this physician, are you aware that your loved one always has the right to change physicians?

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## PAIN & RELIEF FROM PAIN

29. Is your loved one in pain or suffering from various symptoms right now? If so, what actions has your attending physician taken to alleviate this suffering?

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30. Is your attending physician experienced in treating pain which occurs in terminal illnesses or would another physician be preferable at this point?

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31. If your loved one has cancer (or another potentially painful condition), does your attending physician subscribe to the standard protocols for treating pain which were established by the U.S. Department of Health & Human Services, Department of Public Health and published in the Clinical Manual for the Treatment of Cancer Pain? (Any physician experienced in treating pain in those suffering from cancer will immediately know which manual this is and what it says about treating pain). If you do not know the answer to this question, have you directly asked your physician if he or she does agree with this protocol? (If he does not, you may have great difficulty achieving pain-control and comfort for your loved one).

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32. If your loved one has cancer pain that has been difficult to relieve, has your physician suggested or mentioned palliative chemotherapy or radiation for the purpose of relieving that pain?

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33. Is your loved one in pain related to diseases of the bones or nerve involvement due to AIDS or other diseases? Is your physician willing to explore various alternative methods of treating such pain? What has your physician told you about how he plans to treat such pain? Is your physician of the belief that large doses of narcotics alone are sufficient to alleviate the pain in bone or nerve-related pain? If so, will your loved one suffer needlessly or die prematurely because narcotics alone are insufficient to treat such pain?

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34. If your loved one is experiencing severe abdominal pain, has any nurse or physician checked for bowel impaction or severe constipation? If there is bowel impaction, what has been done to remove this painful condition?

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35. If your loved one is experiencing severe abdominal pain and there is no bowel impaction or severe constipation, is the pain possibly caused by abdominal spasms? If narcotics are ineffective in relieving this pain, has the physician ordered medications to relieve abdominal spasms? Has the physician even considered if abdominal spasms are occurring?

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36. If your loved one is experiencing any sort of pain (which has not been relieved by the current use of medications or other interventions), what is the plan for relieving such pain? Have dosages been adjusted or other medications been ordered? Are there any special medical interventions which may be used to assist in relieving the pain?

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## **TRAGIC LESSONS FROM PATIENTS MISTREATED BY HOSPICE**

Most people find it inconceivable that a hospice would mistreat its terminally ill patients or their families. However, hospices, like most health care providers, are now administered by executives dedicated to their own personal profit as well as the financial profit of the organization. In the case of some "non-profit" hospices, the administrators are still extremely well-paid, while some patients do not receive the care that they need, the care that they are legally entitled to and the care which the hospice "promises" it will provide! Hospices which consciously choose to not honor and respect the needs and rights of the terminally ill are called "rogue hospices."

These rogue hospices publicly promote themselves as among the very best providers of hospice care. From the outside, you would not know that you were dealing with a rogue hospice. However, these hospices routinely skimp on the services they provide. They bill to Medicare or Medicaid for full services when they actually do not provide full service. They consciously commit health care fraud. These cases are well-documented in the U.S. Office of Inspector General records within the Department of Health and Human Services. The U.S. Attorney's Offices throughout the country are kept busy prosecuting health care fraud committed by these rogue hospices and other agencies who choose to take the risk of committing fraud, because they do not think that they will get caught.

As outrageous as it may seem, many business people who enter health care see it as an opportunity to materially benefit their own careers in a agency which receives "sure" funding from Medicare or Medicaid ... provide the services and the money will be paid. Being a nonprofit hospice does not prevent administrators and Board Directors from awarding high salaries and expense accounts and fancy benefit packages to its top executives. The present-day reality of nonprofit corporations no longer truly reflects the public's image of "dedicated" "charitable" servants of the community.

Patients who enter a hospice expect their medical needs to be taken care of by the hospice. They expect pain control, symptom management, adequate nursing staff to help them when they need it and access to all the medications needed to relieve their suffering. Families expect the hospice to meet their needs for counseling, whether it involves social workers, chaplains or other spiritual counselors, dietitians or other services.

The law requires the hospice to provide all the services needed to meet the needs of the patient AND the family with regard to the terminally ill patient, the family/care giver.<sup>(17)</sup> When the hospice fails to provide all the services actually and desperately needed, it is more than just a betrayal of the trust given the hospice by the patient and family, ... it is

an abominable exploitation of the most needy patient care populations in the health care industry. It is also a violation of federal and state law for a hospice to exploit its patients by not providing the services they need and which they are entitled to receive.

There are many hospices which provide wonderful care. "Rogue" hospices do not respect the laws:

- many hospice patients have *not* received adequate pain medications,
- many have *not* received adequate nursing staff to cover their nursing needs at home in times of crisis (Continuous Nursing Care in the home),
- many hospice patients may be over-sedated against their wishes, or over-medicated with narcotics for pain against their wishes (with consequent premature deaths occurring), and other tragic mis-treatments.
- Many hospice patients have been terminally-sedated so that death occurs due to dehydration (and not their terminal illness). Death is imposed!

Some doctors have an agenda of their own: to "over-sedate" some patients, because the doctor believes that very "aggressive" sedation is effective in pain control or terminal care in general. Sedation is very effective in helping to keep pain under control when used in combination with the correct pain medications for the patient's condition. However, if a physician sedates the patient even when the patient does not wish to be sedated, the physician is violating the patient's right to choose his or her own treatment plan. These physicians simply believe in a "treatment protocol" and apply it indiscriminately to all of their patients. That is why it is important to know your doctor's philosophy on controlling pain. Will the doctor honor your wishes and adjust the plan accordingly?

Some doctors routinely do not honor the patient's wishes concerning their own care and medical treatment. We have directly seen for ourselves patients who died in agony begging the doctor for relief from pain, when the doctor simply refused to follow accepted standards of care in hospice/palliative medicine and refused to increase the dosage of pain medications! It is likely that in every major city there are a few doctors like that, who either do not care if their patients suffer or do not believe in treating pain properly to relieve it!

Some patients wish to die at home with their family by their side. That is a simple request and in many cases, the family is willing to help out 24 hours a day. Even with the family helping out 24 hours a day, some families do not have the knowledge or skill or experience in working with terminally ill patients. They do *not* know how to give narcotic or other medications to reliably relieve the symptoms of their loved one. It is for the hospice RN case manager to teach them what they need to learn. If the family is not

teachable, does not have the knowledge to allow them to learn how to give medications, or if the family is simply too weak physically to provide the care, then hospice is required by law to provide the needed nursing care at home during a period of crisis.

## **JOSE ALVAREZ' HOSPICE EXPERIENCE**

[His wife's perspective]

Jose was a father, husband, brother and loved family member. We cannot put in words how much he meant to us, and still does. But everything changed when he became sick. Then it became worse and we learned that it was a terminal disease! "Nothing could be done," the doctor said. So we were told that hospice should be called in. They know what to do, we thought. They will take care of everything. We were wrong ... oh, so wrong.

When the hospice staff came to our home, they told us that Jose was so sick that they had to take him to their facility. Jose said he wanted to stay at home, and we begged the hospice to try to keep him home with us. Couldn't they bring some nurses in the home, like we had heard they do?? "No," they said. They had to bring him to the hospice's own facility, because there were no nurses available to take care of him at home. We had no choice but to move him to the facility ... where he did not want to be, where he did not want to go.

His brothers and relatives wanted to keep him at home and so did we. But we did not know what else to do. Jose begged to go home every day at the hospice care facility. "Let me go home," he said, over and over. But no one at the hospice did anything to bring him home. At least, until we spoke with one nurse. He listened and told us he'd ask the hospice management what they could do to bring Jose home. We wrote a letter which was given to the hospice management and placed in the chart as well. But the hospice management never responded. They ignored us, and ignored Jose's wish to go home, even though he begged to go home every day. Did the hospice management care? No, not at all!

We felt terrible that we could not bring Jose home. And later we learned that the hospice had lied to us! Because Jose's symptoms were so severe, the hospice was required to help us at home and try to control his symptoms, but they never tried at all. Of course, now we know that they were billing for room and board at their facility and getting money from our insurance company for the hospice services too. It was all about money, nothing about what was right for Jose. We did not know then what the law was, what Jose's rights

were. Unfortunately, we cannot go back and change things. We wish that we could have known then what we know now.

When a complaint was made to the state inspectors, they investigated and told us that the hospice was in violation of the law. They should have helped Jose at home. But the hospice management was only interested in money!

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## **DENINE RUHOFF SHARPE'S HOSPICE EXPERIENCE (HER MOTHER'S PERSPECTIVE)**

Denine was our middle child of three. She was an outgoing and happy girl who had many friends. She had a good sense of humor and was funny and laughed a lot. When she was 6 years old, I gave her her first cat "Dixie." She loved animals and people.

She and her brother were in the Civil Air Patrol when she was younger. They searched for lost aircraft. Denine loved sports: ice skating, tennis, and usually won first place at track meets. She was also very artistic and did painting and sculpting. As she grew older, we took tennis lessons together and she was active in numerous sports including skiing, baseball, tennis and handball.

We traveled together to Europe, visiting Poland, Germany, and Paris, France. She also went to London with friends. She traveled all over the U.S. and backpacked in various States.

Denine and I enjoyed going to plays and concerts. We saw Phil Collins, Michael Bolton, the show "CATS" and "Fiddler on the Roof," and many others.

Denine had so many friends and enjoyed life very much. Every day was a new experience to look forward to. We belonged to health clubs together. She was always interested in health and staying healthy. There weren't enough hours in the day, because she wanted to do everything. She even took auto mechanics in school and could change her car's brakes by herself!

When she entered college, she could not decide what she wanted to major in. She wanted to major in everything but decided on a double-major: environmental science and criminal justice. She graduated from Western University in 1992.

She began work at the County Jail in the intake department and met her husband Rodney who also worked there. Denine wanted to have many children.

But Denine started feeling sick with abdominal cramps in October of 1994. She went for examinations at the Grand Valley HMO in Grand Rapids, Michigan where an appointment was arranged with "the doctor." He told her she had ulcers and prescribed various medications. She continued to have abdominal cramping and began losing weight. Diarrhea and constipation became a serious problem.

The HMO "doctor" just told her to take MOTRIN for the pain. Then in January, 1995, she started having rectal bleeding and increased fatigue. When she went back to the "doctor" at the HMO, many times, he told her she was "making too much of this" and said, "there is nothing wrong, you have hemorrhoids."

When Denine's pain became more severe, and she mentioned it to the "doctor," he made her feel as if she were a hypochondriac. Finally, after several visits, and much time, her girlfriend Kristy and I told her she needed to demand further tests. The "doctor" had been continually refusing to take x-rays or a CAT scan. Finally, in June of 1995, he agreed to an X-Ray. Two days later he ordered a CT scan, and two days later from that, she was seen by a cancer specialist who diagnosed her as having cancer. She had surgery the following day, June 15, 1995.

After her surgery, we found out that this person at Grand Valley HMO who everyone was calling "doctor," wasn't a medical doctor at all, but was only a physician's assistant (a "P.A.").

All those months when she was suffering severe abdominal pain and rectal bleeding, my daughter Denine had never even been seen by a real medical doctor! And all the nurses there called him "Doctor!" How were we to know he wasn't a medical doctor???

The first time she saw the HMO's real medical doctor was the day following her surgery in the hospital. He actually had the nerve to come to the hospital to see her, but when she visited the HMO, with all her physical problems, he never had the time to see her.

I want to know why all the nurses were calling the Physician's Assistant "Doctor." I want to know why the HMO allowed their staff to call him "Doctor" when he was *not* a doctor! Denine relied on the staff there and believed he was the doctor.

When the cancer specialist diagnosed cancer, he told us he was "sure" he could remove all of the cancer because of Denine's age. We were all so scared. Her sister, Sheryl, her brother Brian and his wife Tammy, her close girlfriends Kristy, Diana and Robin, and I, we were all so scared!

Then, after surgery, Dr. Downy came out of surgery and walked over to me and said what every mother dreads, and my life stopped. He said, "I'm sorry, I never dreamed I'd find this ... She's going to die! ... She has three or four months" [to live]. I could not stop screaming. That is all I really remember. I do not even know how I got home. But I do remember crying all night. Everyone was crying and screaming when we were at the hospital. It was a "nightmare from hell." And it was just beginning.

My beautiful fun-loving daughter, my daughter who loved everything in life, was dying! I prayed every night that God would cure her and that he would take me instead. I wanted to die. "Please!" I thought and begged. It is so difficult to live now and go on with daily life. I miss her SO much!

Within a matter of four days, from the time the "doctor" finally agreed to have an X-Ray taken, up to the time of the surgery, we arrived at the end of all our lives as we knew them.

About three days after Denine's surgery, June 18, Rodney proposed to her and on July 7th, they were married. She was beautiful. A beautiful bride ... and so happy, yet so sad, because she knew that unless God granted her a miracle, she would only live a few months more. Rodney made her happy.

Denine and Rodney lived with me from July, 1995 through April 1996 at my home. Then, they moved into the home that they had built in Cedar Springs, Michigan. I did not want Denine to move. I wanted to take care of her, but I also knew she needed as normal a married life as was possible, under the circumstances.

Chemotherapy started about 6 weeks after her surgery, but soon she was unable to eat. The doctor inserted a central IV line that was placed into her heart. She was fed totally by Intravenous TPN from November 1995 onwards. We watched as Denine grew weaker and weaker, and finally, we called in a local hospice to help care for her.

Rodney had learned to give Denine all her medications by IV, and between Rodney and myself (I'm an R.N.), we gave her all the IV meds and TPN she needed.

Denine had extremely severe pain and started to develop tremors at times too. Her attending physician refused to increase the pain medications when we called to beg for pain relief. Even some of the on-call doctors refused to increase the pain medications enough. We felt there was no one to help us, no doctor who would listen. Sometimes the doctor even yelled at us while on the phone.

Denine was in such severe pain, but always kept her eyes on God and loved everyone. She did not want any of us to feel badly because of her pain, but she could not help herself, and cried out moaning in severe excruciating pain. The doctors never gave her pain relief and they even refused point-blank to order an anti-seizure medication she needed to prevent a seizure. She had a Grand Mal seizure at the end and passed on. She never needed to suffer that way, because the doctors had refused to order what she

needed to relieve her pain and seizures. I've heard that when patients are younger, they often need more pain medications to relieve their pain, but the doctors would not listen.

The hospice management refused to intervene on Denine's behalf. They did not want to upset the doctor who belonged to one of the largest oncology groups in Grand Rapids, Michigan, because they thought they might lose the referrals of terminally ill patients to them. So they kept quiet and told all the nurses not to "offend" the doctor. What did they care about my Denine?? Nothing. The nurses cared, but the hospice management (which controlled them) would not let them advocate for Denine. The Hospice's medical director was required to intervene on Denine's behalf, but she never did. Denine passed away on August 30, 1996. She was 29 years old and just beginning life!

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## **PROBLEMS AND COMPLAINTS ABOUT HOSPICE SERVICES (WHAT TO DO)**

While we all hope that you will not encounter any problems in hospice care, the reality is that problems can and do occur. Any problems you encounter which arise out of the hospice care being provided should be mentioned promptly to the RN case manager assigned to your loved one's case. Clear communication about what the problem is can go far to resolve many problems. Most hospice staff are extremely dedicated and caring and will do whatever they can to help you.

Problems with symptom management and pain control should be immediately called in to the RN case manager. If it is after regular office hours, then you should call the hospice's on-call nurse for advice. Sometimes a little information on how the physician allows you to adjust the medications being given will help you know how to deal with a situation that arises. Sometimes certain medications may need to be stopped, while others may need to be given without fail on a regular basis every few hours.

The hospice is required to make an RN available to come out at any time to assist you and your loved one if needed for symptom management or pain control. Hospices have nurses "on-call" whose job is to visit patients after hours and over night if necessary. They are experienced in dealing with the types of crises that can occur in terminal illnesses. Do not be hesitant to call. The hospice will give you a telephone number which you can call at any time after regular office hours for assistance.

If you find that your loved one is still in pain or experiencing distressing symptoms, even after clearly communicating with your RN case manager or attending physician, then you need to speak with the hospice's medical director yourself. The medical director is authorized to intervene on behalf of your loved one and give medical orders for medications or treatments, if necessary. You also have the right to change physicians to get the care that is necessary to maintain your loved one's comfort and relief from distressing symptoms. If the hospice medical director does not intervene, you can speak with the hospice's manager directly. In any case, should all these attempts fail, federal law guarantees you the right to change to another hospice of your choice.<sup>(18)</sup>

It is important that you write down any complaints you have about a hospice. Writing it down will help clarify the issues. Always remember to include the dates, names of persons involved, the hospice ID/case # for your loved one, and any relevant information. Clearly list the problems which occurred. Complaint about a hospice can be sent to the hospice's management for feedback. In addition, if the problems appear to be due to poor

management, negligence or even intentional management policy, you should make a written complaint to your state's Bureau of Health Systems or Department of Health Services (names vary from state to state).

Call your state's administrative offices and ask which department licenses and certifies hospices. Ask for the specific department that handles complaints about hospices. It is extremely important that you send your complaint in writing, dated, signed and with a return address and phone number so they can contact you for more information if necessary. You can include the hospice's own patient ID # for your loved one to help the state locate the correct medical record. It is wise to send complaints by certified/return receipt U.S. mail to have a record that the state received your complaint.

If within one month you do not receive any confirmation from the state itself that they received your complaint, directly telephone the Department which inspects and surveys hospices to see if they received your complaint. Your persistence can help improve hospice care for other patients and families. You may be reluctant to go to the trouble of making a complaint, but not making a complaint is the reason so many problems continue to exist! By officially making a complaint, you will be helping to stop these problems in the future. We urge you to voice your concerns in writing and let other people know. Health care will only improve if you and others speak up. You can make an important difference.

If you believe that services were not provided to you which should have been provided, this can also be included in a complaint to the state. Because hospices are reimbursed on a per-diem basis, meaning they get paid for every day your loved one is in the program, they are obligated by law to provide all services you need for the care and treatment related to the terminal illness. If you feel you needed or have requested certain services which you know were appropriate and the hospice still failed to provide that service, health care fraud may be occurring and should be reported to the regional U.S. Office of the Inspector General and U.S. Attorney's office for your area. (See the section on Links to Report Fraud).

## **FOR-PROFIT AND NONPROFIT HOSPICES**

Whether or not the hospice you use is a "for-profit" corporation or a "nonprofit" corporation should not make a difference in the quality of care you receive. The regulations are exactly the same. However, in reality, it may make a big difference! For-profit hospices (especially those that are part of a huge hospice corporation or chain of

hospices) have been found to, in general, provide fewer services than nonprofit hospice agencies.

All licensed and certified hospices must comply with state law and the Code of Federal Regulations governing hospice care: 42 CFR part 418. However, it must be noted that there are some large for-profit corporations which are "buying up" hospices all over the United States. Some of them are using ruthless competitive methods in an effort to create "hospice monopolies" in certain areas of the country. Their efforts may result in the destruction of many smaller, nonprofit charitable hospices.

For-profit corporations are organized for the purpose of making money and paying dividends to their stockholders. Nonprofit corporations are organized for the purpose of fulfilling the nonprofit mission of the corporation. Although it would seem that nonprofit hospices would naturally provide better care than for-profit hospices, some nonprofit (as well as for-profit) hospices have been found guilty of health care fraud. The best indicator of whether or not you should choose one hospice or another is the direct personal reference from someone you know who has had recent experience with specific hospice services.

It is not realistic to assume that all for-profit hospices provide less care than nonprofit corporations. But because hospices are paid on a per-diem basis for every day the patient is enrolled in the program, any hospice which "skimps" on services can increase its profits at the expense of the patients and families. Any hospice which you use could provide excellent services. You will need to be knowledgeable about the services which you are entitled to receive, be assertive in advocating for the needs of your loved one and your family, and be involved in the decision making which occurs.

Some hospices (nonprofit as well as for-profit) have constructed inpatient hospice facilities of their own. These facilities cost a lot to operate and must have patients to fill the beds and cover overhead of the hospice. Because of the hospice's overhead, some hospices routinely manipulate patients into their own facilities, even when the patient wishes to remain at home to die. By keeping the beds full, the hospices can charge room and board fees to increase their profit margins or decrease their losses. Do not let any hospice "railroad" you into its facilities when it is against your wishes. You have the right to make your own decisions whether to have your loved one stay at home till the end or transfer to a facility. Whether "for-profit" or "nonprofit," the hospice is required to provide the care that meets your needs related to the terminal illness.

## **HOSPICE FRAUD & SCAMS YOU MAY ENCOUNTER: (HOW TO AVOID THEM)**

There are numerous documented cases of fraud occurring in the hospice environment as well as in every other health care field: i.e. hospitals, nursing homes, home health care, HMO's, insurance, etc. Of course, if you only read the newspapers and watched TV you would never know it at all. Hospice organizations routinely deny or minimize the significance of fraud in hospice, often stating that these are very rare exceptions and that most hospices provide excellent care. However, those of us who have worked directly in the hospice industry know from the inside that it is too easy for hospice administrators to set up situations that result in fraud.

Why Hospice Fraud is So Easy to Perpetrate:

- People generally trust their nurses and other health care workers. This is especially true when the nurse comes to care for the dying. People simply cannot imagine that the hospice itself will take advantage of the patient it is supposed to serve.
- Hospices (especially the nonprofit hospices) are often viewed as charitable, compassionate servants of the dying, when some of the hospices are actually ruthless businesses that are like wolves taking advantage of the sheep. News media are reluctant to report documented cases of hospice fraud, because the trend of the media is to promote hospice and the care of the dying. How can the media outlets, such as newspapers, TV and radio stations report on violations by local hospices when they have recently published articles promoting the very same hospices committing the fraud?
- Hospice, because of its image as a compassionate service, attracts prominent business leaders in the local communities, and many of these prominent business leaders serve on the Board of Directors of the local hospices. The "old boy" network protects the hospice even if fraudulent practices are occurring. This network blocks news coverage, blocks action by local governments (even at the state government level) and effectively hushes up the serious abuses by hospices which are occurring.
- As unbelievable as it may be, hospice administrators often *DO not* teach their staff the full and complete regulations governing hospice care! They often give their staff inaccurate ideas about the regulations, saying that whatever the hospice is doing is absolutely legal, when it is actually felony health care fraud!

- Hospices manipulate their staff into situations where they cannot provide the care needed by the patient, due to intentionally created shortages of staff in key areas such as "Continuous Nursing Care" for patients in crisis in their own home. By not making the effort to actually hire adequate staff, the administration makes sure they cannot provide nursing services as needed in the home, and the patient is forced into the hospice facility, against his will!
  
- Hospices get paid on a "per-diem basis" which means they get a set amount of money per patient signed on, for each day the patient is enrolled in the program, regardless of how many services or medications they provide. The system of payment financially rewards hospices which skimp on services and enroll more patients.
  
- Hospice patients and families are in most cases completely isolated from other patients and families who might give them information which could protect them from fraud or inform them of their rights. In most cases, families are living at home completely immersed in the time-consuming and exhausting work of caring for their loved one.
  
- When patients enroll in the hospice programs, the hospice admissions staff do not always provide full, informed consent. Since the patients and families are not fully informed of their rights, they do not know what services they are entitled to receive.
  
- Patients and families are in crisis mode, grieving the imminent loss of the patient; they cannot muster the energy to fight the hospice's deception or exploitation, even if they do know that they're being taken advantage of.
  
- There is so little time, in many cases, for the patient or family to resolve problems which the hospice may be causing, before the patient dies. So when a hospice under-serves the patient and family, it is out of the picture before anything can be corrected. Complaints from family members can fall on deaf ears at the hospice, and appeals to higher levels of management can result in patronizing insincere apologies from administrators who are paid to simply make the problem go away. What good does it do for the hospice to apologize after the patient has already died, or the family and patient have suffered tragically as a result of a rogue hospice's intentional wrongdoing?
  
- Staff who cooperate with a hospice's plans for fraud are rewarded by promotions and given power within the organization. The hospice can give pay raises to those

who go along with the policies, even though the policies violate the federal and state standards of care for the industry.

- Staff who complain about problems in the hospice are routinely harassed, intimidated and made to feel so uncomfortable that they resign, leaving behind them staff who are so afraid of speaking up that they keep quiet in order to save their jobs.

While some hospice staff and administrators may be shocked by the thought of such abuse occurring, their shock is only to be matched by their naivete. Those hospice staff and administrators who have integrity cannot believe that anyone would conceivably take advantage of the dying. Sadly enough, many do.

### Common Examples of Fraud & Scams in Hospice

While many patients, families, and staff will find it difficult to explain fraud in hospice, fraud does occur. Many staff are unaware of the fraud occurring in areas other than their own area of the hospice's various departments. However, many staff are aware of such abuses yet remain silent. Taking advantage of the dying is one of the most despicable crimes one can think of. Yet there are, unfortunately, unscrupulous executive level hospice administrators who have no qualms about violating regulations and patients' rights in order to cash in on the opportunity to personally make extremely large fortunes while skimming on services to the patients.

All areas of hospice care may be subject to fraud of some kind; there is no area of hospice care that can be ruled out as a possible area for fraud. What must be kept centrally in mind is that the hospice must provide the services needed to meet the actual care needs of the patient. The frequency of services and type of services is *not* determined by the hospice's apparent problems in staffing; the frequency and type of services is solely to be determined by your needs! The hospice is required to meet the needs of the patient and family. Some examples of hospice fraud are:

- Hospices can reduce the frequency of home health aide visits to the patient, so the patient is visited less often than really needed.
- Hospices can reduce the frequency of RN case manager visits to the patient by requiring the RNs to take on overly large caseloads or reducing the number of days each RN works per week. RNs may simply telephone to the patient or family to check on the patient's condition. A telephone call cannot substitute for an actual on-site physical assessment of the patient's condition by the RN.
- Hospices can reduce the availability of RNs, home health aides, counselors, chaplains, bereavement staff, social workers and dietitians by consciously

choosing to *not* hire adequate staff, or delay the replacement of staff who resign. Without adequate staff being hired by the hospice, these hospice staff will have overly large caseloads and will not be able to visit and serve the patients according to the actual needs of the patient.

- Hospices sometimes use licensed practical nurses (LPNs) or home health aides to perform tasks which only registered nurses (RNs) may properly perform. They may use LPNs or home health aides in roles which require an RNs supervision, but not actually provide adequate RN supervision.
- Hospices can skimp on the medications given to the patient for pain! How? Probably every community has physicians who order inadequate or ineffective medications for pain control. Some medications for pain can be quite expensive. The hospice is legally obligated to make sure the patient gets the medications needed to control the pain and maintain patient comfort. When a physician does *not* order adequate pain medication, some hospices may refuse to intervene on behalf of the patient's comfort. They choose not to question the physician's orders and thereby leave the patient in pain, but the hospice saves money by so doing!
  - As cruel as it may seem, some hospices refuse to provide oxygen to patients who are short of breath or who need oxygen for other reasons. The staff tell the families it is not needed, even if the family make suggestions or inquire about it. The hospice saves money by not having to pay for the oxygen.
  - During a crisis, hospices can refuse to provide continuous, around-the-clock nursing in the patient's own home (not a hospice facility) and tell the family and patient that the hospice doesn't have enough staff to provide care in the home. When the hospice tells the patient and family that there aren't adequate staff to provide care at home and thereby keep the patient at home, the patient is often manipulated against his or her will into the hospice facility, where the hospice will then collect fees for room and board, which it would not receive if the patient were kept at home.
  - Even after manipulating a patient against his will into its own facility, the hospice can still bill Medicare, Medicaid or private insurance for the more highly reimbursed level of care, such as Continuous Nursing Care or Inpatient Level of Care. The Continuous Nursing Level of Care may be billed if the facility is licensed as a "home" and not as a nursing home or hospice inpatient facility.
  - Hospices can double-bill patients by asking patients or families to privately pay out of their own pocket for services which already are being reimbursed, or will be reimbursed, by Medicare, Medicaid or private insurance companies.

Because of the isolation of the hospice patient or family, the fraudulent billing to the patient or family may go undetected completely. If the patient has already died and the family wants to put the whole matter behind them, who will report the additional billing to the Office of Inspector General? If the patient and family do not know what is being billed to Medicare, Medicaid or private insurance companies (and they do not know what the hospice is billing) they have no way of realizing that double-billing is occurring. If confirmation of reimbursement from Medicare, Medicaid, or insurance companies arrive in the home several months later, or even later than that, the family will often not even read the confirmation of billing or will not understand that double-billing has occurred.

- Hospices can make fraudulent or otherwise illegal arrangements with nursing homes or hospitals for referrals. Kickbacks to the hospital or nursing home for referring patients to the hospice are illegal. Patients and families would have no way of knowing about such kickbacks.

## What to Look For

Whatever your particular situation, if your loved one is *not* getting the services needed, if the hospice is trying to talk you into transferring your loved one to their facility against his or her will, if your loved one is *not* being kept comfortable, if there is inadequate staff and you are getting exhausted while caring for your loved one, you must demand that the hospice provide the services needed to meet the needs of the family and patient, whether living at home or in any facility. The law requires the hospice to meet the needs of the patient and the family!

## What to Do

It is crucial that you read all the printed literature, documents and contracts you have with the hospice. These pamphlets, brochures, contracts and papers must (by law) inform you of your rights to the various services available through the hospice. Most patients and families do *not* read all this literature, and thereby they lose their greatest protection from exploitation ... **KNOWLEDGE OF THE REQUIRED SERVICES.** Knowing what services are required to be provided will allow you to make informed decisions about the care your loved one receives. Knowing what services are required will help you protect your loved one from exploitation.

If you are not getting the services needed to meet the patient's and the family's needs, you need to speak with the RN case manager. If you get the runaround or sophisticated excuses, you must demand to speak with the hospice's medical director and Manager. If you still do not get proper action to correct the problem, put a complaint in writing and send it to your state's Bureau of Health Systems (which is responsible to inspect the hospice) immediately and also give a copy to the hospice. You can count on the hospice to move quickly to correct the situation if you actually put a complaint in to the state. If you believe there is actual fraud occurring, do not hesitate to contact both the U.S. Office of Inspector General and your regional U.S. Attorney's office. They will investigate your case and may find confirmation of long-standing patterns of hospice fraud. For direct links to the OIG and U.S. Attorney's Office/Department of Justice, see the section within this website for "Links to Put in a Complaint about Hospice Fraud."

## **What the Inspector General Says About Hospice Fraud in Nursing Homes**

Although hospices and hospice organizations will deny it, the United States Department of Health and Human Services - Office of Inspector General (OIG) has investigated and clearly documented many cases of fraud in hospice. Because of so many cases of hospice fraud occurring, in 1995, the OIG released its Fraud Alert Bulletin detailing types of hospice fraud that may occur when the patient is residing in a nursing home. This report is available directly from the OIG at its website at the following web address:

<http://www.dhhs.gov/progorg/oig/frdalrt/110295.html>

or you can see it in written form published in the Federal Register: November 2, 1995 (vo. 60, Number 212) which is available at any major public library in your area. We provide this report herein for your convenience:

[Federal Register: November 2, 1995 (Volume 60, Number 212)]

[Notices]

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Inspector General

Publication of the Medicare Advisory Bulletin  
on Hospice Benefits

AGENCY: Office of Inspector General, HHS.

ACTION: Notice.

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**SUMMARY:** This Federal Register notice sets forth a recently issued Advisory Bulletin, in conjunction with Operation Restore Trust, that identifies important eligibility and other information involving the current Medicare hospice benefit. This Advisory Bulletin has been made available to consumers, health care professionals and health care associations, and is now being reprinted in this issue of the Federal Register as a means of ensuring public awareness of the purposes of hospice care and the consequences of electing the Medicare hospice benefit.

**FOR FURTHER INFORMATION CONTACT:** Joel J. Schaer, Office of Management and Policy, (202) 619-0089.

**SUPPLEMENTARY INFORMATION:** This Medicare Advisory Bulletin is part of Operation Restore Trust--a joint effort among the Office of Inspector General (OIG), the Health Care Financing Administration (HCFA) and the Administration on Aging within the Department of Health and Human Services to combat fraud, waste and abuse in the Medicare and Medicaid programs. The purpose of this Advisory Bulletin is to inform consumers and health care professionals about certain questionable practices affecting Medicare's hospice program. The issuance calls specific attention to the possible misuse of the hospice benefit, as uncovered through collaborative work undertaken by the OIG and HCFA.

Specifically, the Advisory Bulletin highlights several practices which indicate that some hospice providers may have inappropriately maximized their Medicare reimbursements at beneficiary expense. These practices include:

Making incorrect determinations of a person's life expectancy for purposes of meeting hospice eligibility criteria;

Engaging in marketing and sales strategies that offer incomplete or inadequate information about Medicare entitlement under the hospice program to induce beneficiaries to elect hospice and thereby waive aggressive treatment options that Medicare would otherwise cover; and

Encouraging hospice beneficiaries to temporarily revoke their election of hospice during a period when costly services covered by a plan of care are needed in order for the hospice to avoid the obligation to pay for such services.

A reprint of this Medicare Advisory Bulletin follows.

Medicare Advisory Bulletin

## Questionable Practices Affecting the Hospice Benefit October 1995

The Department of Health and Human Services administers the Medicare program for the benefit of 38 million elderly and disabled Americans. In May 1995, the Secretary of Health and Human Services announced Operation Restore Trust, a joint project of the Office of Inspector General, the Health Care Financing Administration and the Administration on Aging. Among its objectives, Operation Restore Trust seeks to identify vulnerabilities in the Medicare program, and pursue ways to reduce Medicare's exposure to fraud, waste and abuse.

This Advisory Bulletin is a product of Operation Restore Trust. The bulletin describes some potentially abusive practices which have been identified through examination of the Medicare hospice benefit.

### What Is Medicare's Hospice Program?

The goal of hospice care is to help terminally ill patients continue with their normal activities of daily living as comfortably as possible, while remaining primarily in a home environment. To achieve this goal, the Medicare program shifts the focus of medical attention from curative treatment seeking to reverse an underlying disease or condition to palliative or supportive care, including a wide range of medical, social, and emotional supportive services.

To be eligible for hospice services under Medicare, an individual must be certified as terminally ill by hospice medical staff and the individual's attending physician if he or she has one. Terminal illness is defined as a medical prognosis that the patient's life expectancy is 6 months or less if the terminal illness runs its normal course. The Medicare beneficiary's inclusion in a hospice program is voluntary and can be revoked by the beneficiary at any time.

The decision to elect the hospice benefit has significant consequences because the beneficiary waives the right to receive standard Medicare benefits, related to the terminal illness, including all treatment for the purposes of curing a terminal illness. Hospice coverage is divided into four discrete election periods, during each of which the beneficiary must be certified as terminally ill.

The fourth and last election period has an indefinite duration, unless or until the beneficiary no longer meets the eligibility requirement of a prognosis of 6 months or less to live.

### What Problems Have Been Identified?

In the course of reviewing trends in Medicare's hospice program, the Office of Inspector General has learned of activities that should be of concern to beneficiaries who are in hospice or who are considering the option of hospice. These questionable practices primarily involve issues of hospice enrollment and are the subject of ongoing analysis by the Medicare program and, in appropriate cases, investigations and audits by the Office of Inspector General. Some hospice providers, in efforts to maximize their Medicare reimbursement, may knowingly engage in one or more of the following activities:

Making incorrect determinations of a person's life expectancy, for the purposes of meeting hospice eligibility criteria.

Engaging in marketing/sales strategies that offer incomplete or inadequate information about Medicare entitlement and restrictions under the hospice program, in order to induce beneficiaries to elect hospice and thereby waive other treatment benefits.

Encouraging hospice beneficiaries or their representatives to temporarily revoke their election of hospice during a period when costly services covered by the hospice plan of care are needed, so that the hospice may avoid the obligation to pay for these services.

#### Important Features of the Medicare Hospice Benefit

The hospice benefit is restricted to patients with a diagnosis of terminal illness and prognosis of 6 months or less to live.

In several recent medical reviews of beneficiary eligibility for hospice, the Office of Inspector General has found significant inaccuracies in the determinations of terminal illness. These findings have prompted a concern that some hospices may intentionally misrepresent a condition as terminal in order to secure Medicare reimbursement. For instance, investigators have encountered hospices that asked nurse employees to alter notes in patients' records or to otherwise misrepresent patients' medical conditions, in order to falsify the existence of a terminal condition.

There have also been cases where physician certifications of terminal illness have been medically questionable. If a hospice submits claims to Medicare under circumstances [[Page 55722]] where it knows of the absence of a terminal condition, the hospice may be liable for the submission of false claims. Criminal penalties can also be imposed against persons who knowingly and willfully make

false representations about a patient's medical condition which are used to determine eligibility for payment of Medicare or Medicaid benefits.

A hospice should not refuse to address health care needs relating to a beneficiary's terminal diagnosis.

Once a Medicare beneficiary elects hospice care, the hospice is responsible for furnishing directly, or arranging for, all supplies and services that relate to the beneficiary's terminal condition, except the services of an attending physician. Hospice beneficiaries have the right to receive covered medical, social and emotional support services from the hospice directly, or through arrangements made by the hospice, and should not be forced to seek or pay for such care from non-hospice providers.

When a beneficiary is receiving hospice care, the hospice is paid a predetermined fee for each day during the length of care, no matter how much care the hospice actually provides. This means that a hospice may have a financial incentive to reduce the number of services provided to each patient, since the hospice will get paid the same amount regardless of the number of services provided.

Medicare has received complaints about hospices neglecting patient needs and ignoring reasonable requests for treatment. One individual reported that his wife's hospice failed on three separate occasions to respond to telephonic requests for emergency services. He was forced to call a non-hospice physician who arranged for hospitalization. His wife's care required a 26-day length of stay. Although the hospital contacted the hospice the day following admission, the hospice did not visit the patient or in any way coordinate her care during the hospital stay.

The Office of Inspector General also has uncovered situations where duplicate claims were submitted by a hospice and other providers (such as skilled nursing homes and hospitals) for services related to the beneficiary's terminal illness. In a nationwide audit of services provided to Medicare beneficiaries enrolled in hospice programs, approximately \$21.6 million was improperly paid to hospitals and nursing homes for the treatment of hospice beneficiaries. Hospices are required to make financial arrangements for hospitalization, nursing services and all other health care needs related to the beneficiary's terminal illness and included in the hospice plan of care. The cost of these services should be paid by the hospices.

A beneficiary has a right to expect a hospice to provide complete and accurate information about the consequences of hospice election and revocation.

A hospice is obligated to inform beneficiaries or their representatives that by electing the hospice benefit, they waive all rights to curative treatment or other

standard Medicare benefits related to the terminal illness, except for the services of an attending physician. Some hospices inappropriately induce beneficiaries or their representatives to enroll in the hospice program without explaining that hospice election results in forfeiture of curative treatment benefits under Medicare. For instance, some hospices have solicited the beneficiary's neighbors and friends, who in some jurisdictions may act as beneficiary representatives, and who may not be familiar with the beneficiary's medical condition. In these situations, the beneficiary and/or representative may not appreciate that traditional Medicare benefits will be denied once the hospice benefit is elected.

The Office of Inspector General also has learned of hospices which induce beneficiaries to revoke the hospice election if expensive palliative treatment, even for a temporary period, becomes necessary. As a consequence, beneficiaries may then be burdened with substantial co-payments that would not be charged under hospice. It is especially important to note that when a beneficiary revokes the hospice election during the last election period, re-enrollment in the Medicare hospice benefit will be precluded permanently.

#### You Should Be Alert to the Following Questionable Activities

Hospice recruiters failing to notify prospective patients or their representatives that they will no longer be entitled to Medicare coverage of curative treatment if they elect the hospice benefit.

Hospice personnel inducing beneficiaries to revoke their hospice election when more costly treatment is needed.

A hospice refusing or failing to provide or arrange for needed care;

Nursing home residents being induced to elect hospice but not receiving the additional benefits of hospice care;

Non-hospice providers charging Medicare for services to hospice patients that hospices can and should provide, such as counseling or medical equipment.

#### What To Do With Information About Questionable Practices Involving Hospice

If you have questions about the scope of the hospice benefit or the care you are receiving in hospice, you should first consider discussing these matters with your attending physician or the hospice provider. If you wish to report questionable practices, call or write: 1-800-HHS-TIPS, Department of Health and Human Services, Office of Inspector General, P.O. Box 23489, L'Enfant Plaza Station, Washington, D.C. 20026-3489.

Dated: October 23, 1995.

June Gibbs Brown,  
Inspector General.  
[FR Doc. 95-27217 Filed 11-1-95; 8:45 am]  
BILLING CODE 4150-04-P

[THIS IS THE END OF THE OIG ADVISORY CONCERNING HOSPICES]

## **HOSPICE FUNDING: WHY YOU NEED TO KNOW ABOUT IT**

While the hospice's source of funds may be the last thing on your mind, hospices are businesses. The business end of hospice can affect the care your loved one receives. Hospices receive funds from government programs or private insurance, from donations made by the public or other corporations, and from grants donated by charitable foundations. Hospices are reimbursed by Medicare, Medicaid, or private insurance for care provided to the terminally ill.

Except for continuous around-the-clock home nursing care, which is paid for on an hourly basis, all other services are reimbursed on a per-diem basis. Hospices are *not* reimbursed on a fee for service basis: rather, hospices are paid, on a basis of how many days the patient is enrolled in the program and received services: the per-diem basis. In return for payment, Medicare, Medicaid and private insurance companies expect the hospices to provide all services which the patient and family need which are related to the terminal illness.

The per-diem basis of payment places much trust in the hospice management. However, fewer services provided to a patient results in more money retained by the hospice. Obviously, the system can reward fraudulent hospices with increased income while honest, dedicated hospices provide full services as required.

## Donations to Hospices

While nonprofit hospices can solicit as well as receive charitable donations, for-profit hospices can only receive donations. After the death of their loved one, some families suggest making memorial donations to the hospice they used. This is a very significant source of funds to the hospice and helps to cover expenses incurred in running the hospice.

Nonprofit charitable hospices are supposed to provide hospice services to those persons who do not have coverage and cannot afford to pay for care. So when you donate to a nonprofit hospice, there is a greater likelihood that charitable hospice services will be provided.

When you donate to a hospice, you cannot be sure that donations made to the local hospice will actually be used for the purpose you designate. Even if you designate a purpose, there are legal tricks of the trade, or accounting, which can make it possible for a hospice to shift the donated money or other money to other purposes than what you wished. Although there are laws stating that restricted donations must be used for the purpose designated by the donor, certain recent court cases have challenged the strictness with which these laws are enforced. Practically speaking, the government does not always look into what a hospice may do with any donations. While donating directly to a nonprofit hospice allows you claim a charitable federal tax deduction, you can only be sure that your money is used for a particular purpose if you personally buy something and donate it to the hospice. Some hospices have several branch locations covering a large area. If you donate to one hospice, the management may take the money and transfer it to a completely different location ... or it may use the money to help pay for unreasonably high salaries for executives.

For-profit hospices have no obligation to provide services to anyone who does not have coverage from Medicare, Medicaid or private insurance. They can turn people away and tell people to go elsewhere. If you do choose to donate to a for-profit hospice, just remember that the for-profit corporation may take that money and pay its Chief Executive Officer many hundreds of thousands of dollars each year in salary and benefits!

## No Need to Pay Privately for Continuous Nursing Care Services

Whether or not your loved one has Medicare, Medicaid or private insurance, you should never have to pay out of your own pocket for hospice services if your loved one has symptoms which are out of control. If your loved one has symptoms which are uncontrolled, then the hospice must provide continuous nursing care until the symptoms are managed as part of the "Continuous Care" level of care. If a hospice asks you to pay for continuous nursing care out of your own pocket, when you already have Medicare, Medicaid or private insurance, it is very likely committing health care fraud! It is important that you report this to your regional U.S. Office of Inspector General and U.S. Attorney's office. In some cases hospices have been billing the patient and family privately while simultaneously billing to Medicare, Medicaid or a private insurer. Double-billing is a very real and despicable scam committed by rogue hospices taking advantage of the dying. Do not let this happen to you!

## Charitable Provision of Hospice Services

If you do not have any coverage by Medicare, Medicaid or private insurance, a nonprofit charitable hospice can provide services to you free of charge as part of its charitable mission. The nonprofit status of the hospice often requires it to provide charitable services. Find a nonprofit hospice if you have no coverage, the nonprofit hospices are dedicated to the mission of serving those in need.

## **HOSPICE ORGANIZATIONS: LOBBYING GROUPS**

There are many organizations on both state and national levels which promote hospice. These organizations are not consumer-advocacy groups, but lobbying groups which protect the interests of corporate hospices. Even though they often state that they are interested in promoting quality hospice care, they are not going to publicly admit the severity of fraud in the hospice industry. They act more like PR/Public Relations organizations which publicize the benefits of hospice, and also act as industry lobbying forces to protect the industry and promote laws of interest to hospices.

Hospice organizations are excellent sources for general information about hospice care and may help you locate a hospice. However, quite often they will only notify you of

hospices which are members of their organization. If a hospice exists in your area which is not a member of the organization, you may not learn about it from the hospice organization. Better to simply check your local yellow pages under the listing "Hospices," or ask your attending physician. There are many hospices serving the public, and the quality of care can vary widely.

While you may have read that if you had a complaint against a hospice, you could contact a hospice organization, contacting a hospice organization is not the proper route to take in order to resolve a complaint. Because hospice organizations are made up of member hospices and receive donations from the member hospices, the organization has a vested interest in protecting its own members: the hospices, not the patients. You need to file formal complaints with your state's Department of Licensing and Certification which inspects hospices and investigates complaints. You also need to file complaints with your regional U.S. Office of the Inspector General and U.S. Attorney's Office.

## **HOW VULNERABLE PATIENTS AND FAMILIES ARE TO EXPLOITATION**

When a physician hands out a terminal diagnosis, it is often devastating to the patient and family. There are so many things we may have wanted to do, to share, to say, to experience ... and now, in a moment all of that has changed. There are regrets, dashed hopes and dreams. In some cases, the patient is elderly and has lived a long and full life; sometimes it is easier to accept in such a case, but not always. Even then, there is often much grief and sadness. Out of fear of death, some families and patients can deny the imminence of death all the way up till the very end.

In the midst of a terribly upsetting confrontation with our own mortality and the death of our loved ones, patients and families must make numerous decisions about:  
what type of health care the patient wants,  
where the patient is to live,  
who will help take care of him or her,  
what efforts will or will not be made to revive him or her,  
is a Will made out?,  
how will we deal with being alone?

what type of funeral arrangements should be made,  
what will happen after the death of our loved one,  
will we need to move to another home?  
how will the family manage financially, and so on.

For many, it really is quite overwhelming to deal with the impending death of a family member. Religious faith can help soften the blow, but it is still difficult. When patients and families turn to hospice, they are quite often desperately seeking answers to very urgent questions. The hospice has an ethical and legal obligation to meet the needs of the patients and families: that is the mission of hospice ... to work from the heart in a spirit of compassion.

Because patients and families most often do not know the laws governing hospice care, unethical hospice administrators could arrange for hospice staff to mislead them about any aspect of hospice, and the patient or family would not know if what they were told was the truth or not. We trust health care staff, nurses, doctors, and counselors ... licensed to serve professionally, and we believe they would never lie or deceive us ... of course. When patients and families find out that they have been deceived by health care professionals, outrage is an understated description of how they feel.

But more often than not, the hospice staff are misled by administrators who feed them misinformation about the regulations, and then the staff do not realize that any fraud or exploitation is going on ... even though their instinct tells them something's just not right. Once hospice staff are misinformed about the standards, it is easy for hospices to have the staff do the "dirty work" for them. If they're caught by the police or government inspectors, they blame the staff and deny any personal involvement.

Because it is common to be caught up in the emotional upheaval of the moment, hospices can easily manipulate families or patients into facilities against their will, or simply not provide certain services which the family or patient is not aware of, even though needed. Some rogue hospices sorrowfully tell the patient that they cannot provide private-duty around-the-clock nursing, even when the law requires the hospice to provide Continuous Nursing Care in a crisis. These rogue hospices then refer the patients to private duty nursing agencies owned by the hospice itself and charge the patient for services which the hospice is already billing to the federal government or private insurance ... or the hospice may bill at the routine home care level of care to government and have the patient pay for the continuous private duty nursing care (another form of double-billing).

Why patients and families are vulnerable is not difficult to understand. But when hospices exploit the very patients and families they serve, they betray the trust those patients and families give them, and that is intolerable as well as illegal. Those hospices

which provide quality hospice care cannot understand the fraud that occurs in other hospices. Most staff are so dedicated and caring. But certain hospice administrators are white-collar criminals who happen to have entered hospice administration as an opportunity for self-aggrandizement and high pay. Knowing what services should be provided will help you avoid being exploited.

## **PRIVATE INSURANCE CASE MANAGERS: THERE TO HELP YOU**

If you have private insurance which pays for hospice services, you will be assigned an insurance case manager by the insurance company. The job of the insurance case manager is to make sure that you receive all services which the insurance company is paying for. Because the private insurance company is paying for the services, it can request the hospice to provide the services which are reasonable and necessary to help care for your loved one. The per-diem reimbursement plan is used by private insurers as well as Medicare and Medicaid. So, the hospice gets a lump sum for each day the patient is enrolled in the program, and of course, is expected to provide all the services needed. Whether the hospice actually provides all the services needed is another issue.

When your attending physician certifies your loved one as eligible for hospice, the hospice will contact your private insurance company and explain the plan of care to the insurance company's case manager. The insurance case manager will state whether or not services are covered. In those cases where hospice is covered, the hospice must provide all the services required by the standards of care in the industry: the Code of Federal Regulations at 42 CFR Part 418. The standards of care do not change whether you have Medicare, Medicaid or private insurance. Because the hospice is licensed, it must meet the standards set down by federal and state law. If you encounter difficulties in resolving a problem with a hospice, either in the quality of care or lack of care, you can speak with your private insurance case manager who can assist you.

## **REASONS FOR PROBLEMS IN HEALTH CARE**

It is well-known that there are problems in the health care industry. From the government and private-insurance perspective, health care costs are increasing too quickly and bills

for services are simply too high. On the other hand, health care workers are paid less than comparably trained workers in other fields. Nurses especially are underpaid. Part of the reason is that the vast majority of nurses are women, (women historically, in our society, have been paid less than men for similar work). Many health care workers enter the field out of a sense of service to humanity and caring. For that reason, some feel that they are giving of themselves for a worthy cause, even if under paid.

Even though many health care staff are underpaid, top and middle-level executives of large health care and pharmaceutical corporations routinely receive salaries in the hundreds of thousands of dollars, even millions. Costs for medications, and equipment continually go up. Corporations double-bill for services, medications and equipment. Even bills which are not totally fraudulent frequently contain inflated charges for itemized expenses. These inflationary trends are one reason for health care costs to spiral upward.

The health care field is mostly administered by businesses which aim at cutting their own costs and increasing profits (increasing costs to others). They are no longer controlled by people truly dedicated to the mission of serving others for service's sake. Self-interest and the benefit to corporate shareholders has taken over the administration of the industry. Even nonprofit health care corporations must take in more than they spend in order to stay in business. The competitive nature of business has progressively entered into health care, so that decisions are made based on short-term business goals rather than the good of the community or ethical considerations. When shareholders' business interests control the decision-making process, to the exclusion of ethical and legal considerations, short cuts are taken which result in suffering for patients, families, care givers and health care staff.

Fraud in health care is rampant. For this reason, the U.S. Office of Inspector General (OIG) has launched its Operation Restore Trust. A Fraud Hotline has been established and hundreds of thousands of complaints have been phoned in to the U.S. OIG offices. There is now a large backlog of cases to be investigated and prosecuted. The OIG has hired many new special agents to investigate all the cases of health care fraud.

One well-known intentional violation agencies routinely commit is under-staffing their facilities. The law specifies minimum staffing which must be maintained, but agencies look the other way and assign fewer staff to their facilities anyway. Under-staffing at hospitals is a well-known tactic used to increase the bottom line while patient care deteriorates. The reasoning? If we can get by and provide the services with less expenditure for staffing, so much the better, our profits will increase and the shareholders will be pleased. Are the best interests of the patients the controlling factor? Certainly not!

If a patient suffers, large health care corporations do not really care, so long as the corporation is making money. They do not intend to harm the patients, but they make decisions which they know will result in harm to patients. They consider even a few lawsuits acceptable risks to take on the road to big profit margins. And when the big profit margins arrive, they reward themselves with fat salary increases on a yearly basis while cutting salaries and/or benefits to the staff that directly serve the patients. They replace full-time experienced workers with two or three part-time workers without experience. The part-timers do not get the same benefits, and their hourly wages will be less than the senior, more experienced workers who have been replaced.

Health care corporations have been steadily replacing more highly trained professionals with untrained technicians who get trained on the job for specific tasks or procedures. Physicians are replaced with nurses; nurses are replaced with technicians; registered nurses are replaced with licensed practical nurses or aides. The result? Patient care quality suffers. Of course, none of this is admitted publicly. Public Relations representatives are hired to make all decisions appear to be made for the welfare of the public.

How many HMO's (Health Maintenance Organizations) pay their top executives millions of dollars while patients are denied care they are entitled to receive? Many. This state of affairs is a disgrace and threatens to destroy the fine health care system we have in the United States. If this trend continues, only the very rich or poor will get health care, while the working middle-class may have to accept whatever health care they can get from corporate health plans, if they have any health benefits at all.

Hospices can and do play the same games of cutting corners. Hospice administrators may assign more cases to staff than can reasonably be managed well ... to increase profits. RN case managers, social workers, chaplains, counselors, and home health aides may struggle to cover all the cases they have. Fewer staff hired means smaller payrolls, less expense and the hospice saves money. Quality suffers ... but who will know the difference? If there is a complaint, the administration can blame the staff and intimidate them ... which often is done. Staff fear losing their jobs, so they keep quiet and do the best they can, slowly burning out emotionally in the process.

Of course, ethical administrators will not reward themselves with obscene salaries in the hundreds of thousands of dollars or even millions while patients go without basic care. Not providing the care according to the standards saves the health care agencies money, but violates the law. Most agencies who commit fraud obviously believe that they will not get caught. They also believe that even if they do get caught, the penalties will not be severe: they can plea bargain their way out of it or make a show of correcting the problem by terminating some middle-managers who will take the blame.

Unethical administrators do exactly this every day in the United States! Our health care system must be reclaimed from the white-collar criminals who commit fraud knowingly, while patients suffer. Only by filing formal complaints with the U.S. Attorney's Office and the U.S. Office of the Inspector General will health care fraud be stopped. The public must become actively involved in protecting itself and enforcing the standards of care, whether in hospice or other health care. The time for consumer advocacy in health care and hospice in particular has arrived.

## **WHEN NURSES, ... DOCTORS ... AND SOCIAL WORKERS ... KEEP SILENT**

Although the public invests much trust in the nurses, doctors and social workers who provide health care services, some of them betray that trust by keeping silent when accurate information is needed. Why such a betrayal might occur is easily explained by financial concerns: keeping one's job or power or prestige in the agency.

It is well-known that cover-ups can occur when something goes wrong: in surgery, in the emergency room, in health care in general. Do all doctors readily admit their responsibility if they ordered the wrong medication or the wrong dosage for the patient who died unexpectedly? Do all nurses volunteer the information that they gave the wrong dose or medication to the patient? And when a social worker learns that a patient did not receive certain services which he or she should have, does the social worker (employed by the agency) immediately tell the patient that the agency made a mistake or exploited him??? ... or does the social worker look the other way and keep quiet?

While there are so many dedicated and honest health care workers who do speak up and advocate to protect their patients ... who do admit wrong if appropriate, there are also many who keep quiet when things are not done according to the standard. Those who honestly admit their mistakes may be looked upon as fools by those who cheat every day, and keep their jobs. Day after day we can read in the newspaper of terrible errors made in health care with resulting lawsuits. When the errors first occur, do the patients or families get full information from the agency? Rarely.

Do the hospitals refuse to allow certain doctors to admit patients when the hospital knows that the doctor is not fully competent? Not usually. Only when insurance companies threaten to raise the hospital's premiums would a hospital normally revoke a physician's

admitting privileges. Why? Because the physician is a source of income to the hospital. By referring patients, the physician brings cases to the hospital and keeps things running smoothly, at least financially, that is. As long as patients keep coming in, the hospital will keep quiet. When nurses complain about a surgeon whose death rate on the table is two times the other surgeons, does the hospital revoke the privilege of the physician? Not usually. Does that nurse who complained suffer from retaliation or get blackballed? Yes.

The reason there are so-called Whistle-Blower protection laws is that employers routinely harass, intimidate or terminate employees who honestly complain about problems. Some employees are even physically harmed. Putting the whistle-blower protection laws on the books does not assure protection for employees who make complaints about their employers. Employers have clever, tricky ways of getting around the law, harassing employees in ways that are difficult to document. Annoying them till they resign voluntarily and leave. The employer gets rid of an honest employee who the employer considers a troublemaker, but who is really a servant of the public. Other employees see the retaliation that occurs and decide not to get involved ... to keep silent.

How many nurses or other staff will risk losing their job, simply to speak the truth? Unfortunately, not that many. Many dedicated health care workers have left the field because of the lack of integrity and responsiveness in agency administrators. These health care workers who are leaving care, and because they care, feel that they can no longer work in the field in good conscience, knowing what goes on.

While many leave the field, there are also many who remain dedicated to their tasks. They often pay a high price from the stressful environment. Nurses and nursing assistants have the highest rate of back injuries among all professions, and when a nurse injures her back seriously, her career is often finished. But complain about the lack of help (due to under-staffing ) in transferring patients, and you could get labeled a troublemaker. So injuries continue to occur. While disabled and injured police officers are supported by community fund drives, injured nurses are discarded by the agencies and forgotten. And then if the injury is work-related, the agency plays games to avoid paying workers' compensation benefits. The nurse may end up destitute or completely disabled.

This is not the picture which public relations experts will paint in the media, but it is the hidden side of health care ... hospice included. Health care workers keep silent and simply hope to survive.

## **THE HOSPICE AGENCY'S ADMINISTRATION AND THE "BUSINESS" OF HOSPICE**

Hospices are organized for the purpose of serving the terminally ill and their families or care givers. They are reimbursed for these services by government payors such as Medicare, Medicaid or by private insurance companies. The more patients they enroll in their program, the better their bottom-line profits look. Staff salaries for services provided are the major cost in serving the public. From the strictly business perspective, any way salaries and benefits can be cut will improve the bottom line.

Of course, to remain in business hospices must hire enough staff to provide care to all the patients they enroll. To attract staff and patients they must maintain a positive public reputation. But some hospices may cut corners to improve their financial status. Obviously, any violations the hospice is involved in must be covered up and suppressed. Media must not publicize the violations. How is this accomplished? By getting local big-businessmen to participate on their Board of Directors ... people from the major industries, the universities, the movers and shakers in politics. Involving the bigwigs from local news media is also important. Buying big ads in the papers will help squelch controversial stories from getting published ... the papers look at their bottom line too!

When you or your loved one approach a hospice for care, they will certainly tell you about all the wonderful programs they have to help you. The most important question you need to answer is: Will this hospice be there when we need them? Will they fulfill their duty and provide quality hospice care and all that entails? You need to get personal references from people you know who have used a hospice recently. Compare programs, compare staffing, compare the literature provided and ask questions.

Hospices are service oriented. But hospice administrators are business oriented. They have to be in today's competitive environment; hospices compete for referrals from physicians, hospitals, and nursing homes. The biggest hospice may not be the best ... it may simply be the pushiest, the most aggressive, the most politically-connected, or the biggest advertiser ... none of which guarantees quality. Reputation among those you know is the best indicator of a hospice's quality.

# QUESTIONABLE DEATH: ASSISTED SUICIDE, MERCY KILLING (EUTHANASIA) WHAT TO DO

Some families sometimes wonder if their loved one died because of the terminal illness or if the cause of death was related to the use of medications given during hospice care. Normally, most patients die due to their terminal illness and the medications given are simply to control pain or other distressing symptoms. It is important for families to ask questions and get answers from hospice staff so that all the family members understand the reason for the various medications used.

Communicating with other family members who have questions is important as well, because some family members may not have been present when explanations about medications were given by hospice staff. Sharing this information can reduce stress and worry in other family members. Hospice staff need to be alert to detect these sometimes unspoken questions in family members and to provide explanations about the medications and treatments given during hospice care.

## Assisted Suicide, Death and Murder

In very rare circumstances, cases have been documented and confirmed by the courts, where some physicians and/or hospice staff have given medications in dosages which were either inappropriate or given in larger dosages than that needed by the patient, resulting in adverse reactions and in some cases, even death. Although fully documented and court confirmed cases are "very rare," there are many other cases which are being reported which have not gotten into the court system or where the government authorities have refused to respond at all. Accidental administration of an overdose of any medication is one thing, but intentionally overdosing a patient is in a very different category of action. Intentionally overdosing a patient so as to cause death may be termed "active euthanasia." and if involuntary, "plain talk" would call it murder.

Blatant violations of the standards of care occur when a patient is given a medication that he or she is allergic to and which he directly refuses. A patient always has the right to refuse a medication, even if the medication is appropriate. Some state regulations governing hospice specifically mandate that a hospice patient has the right to refuse a medication or treatment without risking being discharged from the hospice. A basic principle of health care is "informed consent." Consent of a patient means that the patient

accepts the procedure, medication or treatment plan. If a patient does not consent, then a physician or nurse cannot continue to impose a procedure, medication or treatment against the patient's will.

### Assisted Suicide is Not Accepted in Hospice Regulations

Dr. Jack Kevorkian brought the idea of assisted suicide to the forefront of public debate in the late 1990s and the public rejected his views. However, a small assisted suicide. In some cases, health care workers have unilaterally decided to administer "assisted suicide" to willing or unwilling victims of their philosophy of hastening death. An unwilling suicide is not suicide but rather is labeled murder by the courts. Administering potassium chloride as an agent for causing death was one method popularized by Dr. Jack Kevorkian (who was found guilty of violating the law and is now residing in jail).

It is not necessary however, for an overly eager proponent of assisted suicide to use an agent as deadly as potassium chloride. These misguided individuals believe it is their role to hasten death as an act of mercy, similar to how dogs and cats may be "put to sleep" when they become too ill. In our society, putting a person "to sleep"/to death intentionally is labeled murder and is a criminal offense. Even in a location where "assisted suicide" is legalized, administering an agent that causes death to an unwilling terminally ill patient is still considered murder.

Just because a patient has a terminal illness does not lessen the value of that person's life. A patient may be elderly, sick and weakened. However, no one knows with certainty exactly when a terminally ill patient would die. Some patients die within days, others within weeks and some within months or even years. Cases of seemingly miraculous recoveries have been documented. Hospice regulations do not normally allow for the performance of assisted suicide in a hospice program. Performing assisted suicide is illegal in all states except for Oregon. Any individual who informs you that a hospice has a right to perform assisted suicide is misinformed.

## Over-medicating the Terminally Ill: A Method of So-Called "Mercy Killing" or Euthanasia

One method of hastening death used by physicians, nurses and even family members is to administer overly high dosages of narcotics, sedatives or antidepressants when the patient has no need for them. Giving high dosages of narcotics when the patient is not in pain or does not have a symptom requiring the use of that narcotic is inappropriate and may cause death. The most serious adverse effect of giving inappropriately high doses of narcotics, sedatives and antidepressants is "respiratory depression." Respiratory depression can be so severe that breathing stops altogether resulting in death. Families need to ask questions and know exactly why medications are given and to be especially aware of rationales for increasing a dose.

Morphine is commonly given for severe pain in terminal illnesses, especially in cancer pain. In the case of severe pain, extremely high doses of morphine or other narcotics may be necessary to control that pain and have been determined to be safe to administer under the careful supervision of the physician and hospice staff. Morphine is also given for other reasons which most family members may not understand. For example, in the case of end-stage heart failure with respiratory congestion resulting from the weakened heart action, fluid from the blood percolates out through the capillaries in the lung, causing severe respiratory congestion and distress. Medical textbooks list morphine given in combination with a diuretic like Lasix (furosemide) as a classic and one of the most effective ways of reducing respiratory distress and congestion caused by such heart failure.

In the case of overly high dosages of narcotics, sedatives and antidepressants, family members may be the only protection left for a medically comatose patient. "Medically comatose" refers to a patient that would not normally be comatose at that time due to his illness, but who has been placed into a coma (non-responsive and un-arousable mode) by medications being given. The patient can no longer speak for himself, and the family is the only advocate left for that patient. If the patient was willing to sleep during the very last days of his life, then administering high doses of sedatives might be acceptable if the situation warranted it. However, there are physicians and nurses who believe in administering high doses even when the patient is not willing and receptive to those doses.

## Research Demonstrates Some Physicians Approve of Actively Causing Death (Active Euthanasia)

Research studies published in medical journals confirm that a small percentage of health care professionals, including physicians, admit to having hastened a patient's death. It is reasonable to conclude that a larger number have hastened death and that some physicians are not willing to admit what they routinely do in secret. The ethics of physician assisted suicide is currently being actively debated throughout our nation.

A 1998 article in the Journal of the American Medical Association conclusively reports that physician assisted suicide or hastening death is occurring and is not "unheard of" or a "rare" occasion. This report documents cases where the patient wished to die and was assisted by his or her physician to do so. A summary of this article is listed at: [www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?db=m&form=6&Dopt=r&uid=98370629](http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?db=m&form=6&Dopt=r&uid=98370629) "The practice of euthanasia and physician-assisted suicide in the United States." [For complete article see JAMA 1998 Aug 12;280(6):507-13 entitled "The practice

of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians" (at the JAMA website: <http://jama.ama-assn.org/>) written by Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR done at the Center for Outcomes and Policy Research, Division of Cancer Epidemiology and Control, Dana-Farber Cancer Institute, Boston, Mass 02115, USA.]

In the above survey of 355 oncologists, "(15.8%) reported participating in euthanasia or physician assisted suicide." "Thirty-eight of 53 oncologists described clearly defined cases of euthanasia or physician assisted suicide." In the cases reported by that 15.8% of oncologists, "(60.5%) [of the patients] both initiated and repeated their request for euthanasia or physician assisted suicide, but 6 patients (15.8%) did not participate in the decision for euthanasia or physician assisted suicide. [emphasis added] Thirty-seven patients (97.4%) were experiencing unremitting pain or such poor physical functioning they could not perform self-care."

What does it mean that "6 patients did not participate in the decision for euthanasia or physician assisted suicide?" Isn't the obvious conclusion: these patients died without having requested to be killed, without asking for their death to be hastened. Who is deciding who dies and who lives in these situations? Do doctors have the right to play God with the terminally ill, even when the patients have *not* requested such "assistance?"

In the case of a patient who definitely does not wish to die and who is actively "euthanized" against his wishes, that is an even more serious question of medical ethics and law. If you are aware of a situation where the physician, nurse or other family member is giving dosages of medication which have been directly refused by your loved one, you need to directly confront that physician, nurse or family member and ask them

to explain their actions. If you are not satisfied with that explanation, you need to promptly get in touch with an attorney for professional advice.

### American Nurses Association Stands Against Active Euthanasia

The American Nurses Association, the major professional nursing association in the United States has stated:

"The American Nurses Association (ANA) believes that the nurse should not participate in active euthanasia because such an act is in direct violation of the Code for Nurses with Interpretive Statements (Code for Nurses), the ethical traditions and goals of the profession, and its covenant with society. Nurses have an obligation to provide timely, humane, comprehensive and compassionate end-of-life care."

See the American Nurses Association website at  
[www.nursingworld.org/readroom/position/ethics/eteuth.htm](http://www.nursingworld.org/readroom/position/ethics/eteuth.htm)

### Significant Number of Physicians May Approve of Euthanasia and/or Physician Assisted Suicide

It is common knowledge in hospice that there are some physicians in the community who do not prescribe adequate pain medications to properly control the pain of patients with severe pain. It is also common knowledge in the industry that there are some physicians who are extremely "aggressive" in treating pain with narcotics. Being "aggressive" in treating pain is admirable and exactly on target when it comes to hospice care and its reason for being. However, it is also common knowledge that some physicians step over the line and are willing to "push" a patient into death by hastening its arrival through the use of high doses of sedatives and narcotics. Hospices will not normally inform you or your loved one if your physician falls into either extreme category: those who under-medicate for pain or those who over-medicate and hasten death.

An article in the Archives of Internal Medicine, Vol. 160 No. 1, January 10, 2000, <http://archinte.ama-assn.org/issues/v160n1/full/loi81180.html> "Attitudes and Practices Concerning the End of Life - A Comparison Between Physicians From the United States and From the Netherlands (by Dick L. Willems, MD, PhD; Elisabeth R. Daniels; Gerrit van der Wal, PhD; Paul J. van der Maas, PhD; Ezekiel J. Emanuel, PhD) reports the

varying percentages of physicians in Oregon who were willing to increase the dosage of morphine given under various patient circumstances:

- When pain was involved, 97% stated they approved of increasing the dosage of morphine; 53% approved of physician assisted suicide ("PAS") 24% approved of euthanasia.
- When severe weakness and debility of the patient were involved, 36% approved of increasing the dosage of morphine; 37% approved of "PAS"; and 14% approved of euthanasia.
- When patients felt that they were a burden on their families, 24% of the physicians approved of increasing the morphine dosage; 24% approved "PAS"; 7% approved of euthanasia.
- When patients felt that their lives were meaningless, 20% of the physicians approved of increasing the morphine dosage, 22% approved of "PAS", and 7% approved of euthanasia.

See the table of data at: [http://archinte.ama-assn.org/issues/v160n1/fig\\_tab/ioi81180\\_t3.html](http://archinte.ama-assn.org/issues/v160n1/fig_tab/ioi81180_t3.html)

Increasing the dosage of morphine when pain is involved makes sense and leads to improved quality of life for the terminally ill. However, other than hastening a patient's death, what is the reasoning for increasing the dosage of morphine when patients feel their life is meaningless or feel that they are a burden on others in the family? It is obvious that physicians approve of hastening death in many end of life circumstances. 20% or one out of five physicians approved of "PAS" when patients felt their lives were meaningless. 24% approved of PAS when the patient felt they were a burden.

Even more surprising is that 24% of the physicians approved of euthanasia when the patient had severe pain, 14% (or one out of every 7 physicians) approved of PAS when the patient had debility, 7% when the patient felt they were a burden or felt that their lives were meaningless. 7% is one out of 14 physicians who admitted to being willing to act to end a patient's life in those circumstances.

48% of the physicians reported that patients had requested "PAS" or euthanasia. None of the physicians admitted to having performed euthanasia, but 7% admitted to performing "PAS", and 2% admitted to ending a patient's life without a request from the patient.

While these results are from confidential surveys of physicians in Oregon, attitudes of physicians around the country may be quite similar.

## Durable Power of Attorney for Medical Care Does Not Give Right to Over-medicate and Kill a Patient

Some family members who have been approved and appointed by the terminally ill patient as their Representative for medical decisions feel that they have the right to "do anything." However, the regulations regarding the administration of medications do not allow medications to be given in a manner contrary to the physician's orders. Nor does a medical power of attorney allow the Representative to intentionally go against the conscious wishes of the terminally ill patient. Even if morphine or other narcotics are ordered to be given for pain, that does not mean that the family member can give whatever dose they want to give. If death results when a family member gives an over-dosage of narcotic, the family member may be held responsible for that death, rather than the physician.

Even if the killing is done out of a belief in euthanasia or mercy killing, it is still killing or causing death. The district attorney or U.S. attorney for that region would be able to bring a charge against the individual involved and the criminal court system would then be able to rule on what punishment would be appropriate for a person who is found to have intentionally caused another person to die, even in the case of a terminally ill patient.

If a patient or loved one had refused certain medications and those medications were given against his or her will, and the patient later died when those medications were given, you need to consult an attorney who has expertise in criminal law. By discussing the situation with an attorney with expertise in criminal law, the attorney will be able to advise you how to proceed to address your concerns. In some cases, family members have actually gone to the County District Attorney or U.S. attorney and had charges brought against unethical health care staff who have intentionally killed a patient.

## Criminal Prosecutions on Record for Hastening Death

For a discussion of the criminal prosecutions of some cases involving the deaths of patients in health care situations, please refer to the following article posted at the

American Society of Law, Medicine and Ethics website: <a href="http://www.aslme.org/research/mayday\_jlme26/26.4a.html" target="new">  
"Criminal Act or Palliative Care? Prosecutions Involving the Care of the Dying" by Ann Alpers, JD. Ann Alpers is a professor at the University of California at San Francisco's School of Medicine and has taught Medical Bioethics.

## **MAKING A COMPLAINT ABOUT A HOSPICE**

Making a complaint about a hospice which currently is responsible for caring for your loved one or which was responsible for caring for your loved one, but did not comply with the standards of care, is an important step to take in helping to improve the quality of hospice care for all patients, families and care givers. Speaking with the Hospice RN case manager is the first step, then speak with the hospice's medical director and the manager. You have a legal right to speak with these hospice staff. Do not allow yourself to be dissuaded from speaking with them if you have a problem which the RN case manager cannot resolve.

If clearly communicating with the hospice on several levels do not quickly resolve the problem, then you should put a complaint into the state Licensing and Certification Division for your state (See the "State by State Directory of Addresses for Making a Complaint about a Hospice").

In addition, if the hospice is "JCAHO accredited" (by the Joint Commission on Accreditation of Healthcare Organizations) you should also put a complaint into JCAHO (tell the hospice you will be doing so ... and they may hastily change their mind about refusing to provide adequate care for your loved one!). You can directly place a complaint with JCAHO over the Internet by accessing their website and clicking on the "General Public Menu," then clicking on "reporting a complaint" JCAHO's web address is: [www.jcaho.org](http://www.jcaho.org) Their website offers much information about health care and standards of care. Their offices are located at: 1 Renaissance Boulevard, Oakbrook Terrace, Illinois 60181 Tel. 630-916-5800 and Fax. 630-792-5005

If the hospice still refuses, send a written complaint to your state Licensing and Certification Division and to JCAHO, ... by U.S. certified/return-receipt mail clearly explaining your problem and who you spoke with about it.

## Necessary Complaint Information

You can use your own format, (or you can photocopy the form included at the end of this text) but we recommend that you at least include all of the information listed below:

- Your full name, address and tel. number where you can be reached during the day.
- The date you write the letter, along with the Certified Mail Number given to you by the U.S. Post Office.
- The complete official name (see hospice documentation or brochures), address and telephone number of the hospice.
- The complete/full name of your loved one who is or was in hospice care, along with the hospice's own medical record/case number and the date your loved one was admitted to the hospice.
- The type of terminal illness involved.
- The names and titles/profession of those doctors, nurses, social workers, etc. who failed to provide adequate care for your loved one. If you believe that the hospice staff themselves sincerely tried to provide appropriate care, but were not allowed to do so by the hospice management, explain that in your complaint letter.
- The dates, times and circumstances when the hospice failed to provide adequate care or symptom management, etc.
- We recommend that you list each type of problem separately and number the problems. For example, if there were four problems you encountered, then state "I am reporting four problems which I believe violate the standards of care." Then, list each problem by number. This will assist the state surveyors who read your report in clearly understanding what occurred and what to look for.

Be very specific about what shift and what date you are discussing if the problem occurred on a specific shift and time. If the care was poor throughout the time period

your loved one was being cared for, state that and explain exactly what you believe was wrong with the care provided.

It is extremely helpful if you review the federal laws governing hospice (see the section on Federal Laws Governing Hospice: The Uniform Standards of Care) and use the language of the law when describing a problem. For example, you might state, "The hospice failed to intervene to assure adequate pain control," or "The hospice failed to provide nursing care as needed ... " and then explain exactly what happened Remember to always keep a copy of the complaint you sent in for future reference.

## **WHERE TO SEND A COMPLAINT: DIRECTORY OF STATE ADDRESSES**

**WE DO *not* RECOMMEND THAT YOU CALL BY TELEPHONE.  
COMPLAINTS MUST BE PUT IN WRITING TO BE EFFECTIVE!**

If the hospice is "Joint Commission Accredited" by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), then you can also send a complaint to JCAHO'S offices at: 1 Renaissance Blvd., Oakbrook Terrace, Illinois 60181.

STATE OF ALABAMA  
Division of Licensure and Certification  
Department of Public Health - Complaint Division/Hospice  
434 Monroe Street  
Montgomery, Alabama 36130-3017

STATE OF ALASKA  
Certification and Licensing  
Office of Health Facilities  
Dept. Of Health and Social Services - Complaint Div./Hospice  
4730 Business Park Blvd., Suite 18  
Anchorage, Alaska 99503

STATE OF ARIZONA  
Department of Health Services  
Complaint Division/Hospice  
1647 East Morten Ave., Suite 130  
Phoenix, Arizona 85020

STATE OF ARKANSAS  
Division of Medical Services  
Department of Human Services  
Complaint Division/Hospice  
PO Box 8059, Slot 400  
Little Rock, Arkansas 72203

STATE OF CALIFORNIA  
Licensing and Certification  
Department of Health Services  
Complaint Division/Hospice  
714/744 P Street  
P.O. Box 942732  
Sacramento, California 94234-7320

STATE OF COLORADO  
Health Facilities Division  
Department of Health and Environment  
Complaint Division/Hospice  
4300 Cherry Creek Drive South  
Denver, Colorado 80222

STATE OF CONNECTICUT  
Division of Health System Regulation  
Department of Public Health - Complaint Division/Hospice  
410 Capitol Avenue  
P.O. Box 340308  
Hartford, Connecticut 06134

STATE OF DELAWARE  
Licensing and Certification  
Office of Health Facilities  
Complaint Division/Hospice  
Three Mill Road  
Wilmington, Delaware 19808

DISTRICT OF COLUMBIA (WASHINGTON, D.C.)  
Service Facility Regulation Administration  
Department of Consumer and Regulatory Affairs  
Complaint Division/Hospice  
614 H Street, NW, Suite 1003  
Washington, D.C. 20001

STATE OF FLORIDA  
Agency for Health Care Administration  
Complaint Division/Hospice  
Fort Knox Building, #1  
2727 Mahan Drive  
Tallahassee, Florida 32308

STATE OF GEORGIA  
Office of Regulatory Services  
Complaint Division/Hospice  
2 Peachtree, NW, Suite 21-325  
Atlanta, Georgia 30303

STATE OF HAWAII  
Hospital and Medical Facilities Branch  
Department of Health - Complaint Division/Hospice  
P.O. Box 3378  
Honolulu, Hawaii 96801

STATE OF IDAHO  
Bureau of Facilities Standards  
Department of Health and Welfare  
Complaint Division/Hospice  
450 West State Street, 3rd Floor  
P.O. Box 83720  
Boise, Idaho 83720

STATE OF ILLINOIS  
Office of Health Regulation  
Illinois Department of Public Health  
Complaint Division/Hospice  
525 West Jefferson Street  
Springfield, Illinois 62761

STATE OF INDIANA  
Division of Hospice Care  
Department of Health - Complaint Division  
2 North Meridian, Floor 4  
Indianapolis, Indiana 46204

STATE OF IOWA  
Division of Health Facilities  
Department of Inspections and Appeals  
Complaint Division/Hospice  
Lucas State Office Building  
Floor 3, Southwest Corner  
Des Moines, Iowa 50319

STATE OF KANSAS  
Bureau of Adult and Child Care Facilities  
Kansas Department of Health and Environment  
Complaint Division/Hospice  
Landon State Office Building  
900 Southwest Jackson, Suite 1001  
Topeka, Kansas 66612

STATE OF KENTUCKY  
Division of Licensing and Regulation  
Cabinet for Human Resources  
Complaint Division/Hospice  
275 East Main Street, 4th Flr. East  
Frankfort, Kentucky 40621

STATE OF LOUISIANA  
Health Standards Section  
Department of Health and Hospitals  
Complaint Division/Hospice  
P.O. Box 3767  
Baton Rouge, Louisiana 70821

STATE OF MAINE  
Licensing and Certification  
Department of Human Services  
Complaint Division/Hospice

State House, Station 11  
35 Anthony Avenue  
Augusta, Maine 04333

STATE OF MARYLAND  
Licensing and Certification Administration  
Department of Health and Mental Hygiene  
Complaint Division/Hospice  
Metro-Executive Center  
4201 Patterson Avenue, Floor 4  
Baltimore, Maryland 21215

STATE OF MASSACHUSETTS  
Division of Health Care Quality  
Department of Public Health, Complaint Division/Hospice  
10 West Street, 5th Floor  
Boston, Massachusetts 02111

STATE OF MICHIGAN  
Bureau of Health Systems  
Complaint Division/Hospice  
3423 North Martin Luther King, Jr. Blvd.  
P.O. Box 30664  
Lansing, Michigan 48909

STATE OF MINNESOTA  
Facility and Provider Compliance Division  
Department of Health - Complaint Division/Hospice  
393 North Dunlap Street, 5th Floor  
P.O. Box 64900  
St. Paul, Minnesota 55164

STATE OF MISSISSIPPI  
Certification and Licensure  
Division of Health Facilities  
Department of Health - Complaint Division/Hospice  
P.O. Box 1700  
Jackson, Mississippi 39215

STATE OF MISSOURI  
Department of Social Services

Health Facilities Licensing and Certification Dept.  
Complaint Division/Hospice  
615 Howerton Court  
Jefferson City, Missouri 65109

STATE OF MONTANA  
Quality Assurance Division  
Department of Public Health and Human Services  
Complaint Division/Hospice  
Cogswell Building - 1400 Broadway  
P.O. Box 202951  
Helena, Montana 59620

STATE OF NEBRASKA  
Health Facility Licensure and Inspection  
Department of Health - Complaint Division/Hospice  
301 Centennial Mall South  
P.O. Box 95007  
Lincoln, Nebraska 68509

STATE OF NEVADA  
Bureau of Licensure and Certification  
Department of Human Resources  
Complaint Division/Hospice  
1550 East College Parkway, Suite 158  
Carson City, Nevada 89710

STATE OF NEW HAMPSHIRE  
Bureau of Health Facilities Administration  
Health and Welfare Building  
Complaint Division/Hospice  
6 Hazen Drive  
Concord, New Hampshire 03301

STATE OF NEW JERSEY  
Division of Health and Senior Services  
Department of Health - Complaint Division/Hospice  
300 Whitehead Road  
Trenton, New Jersey 08625

STATE OF NEW MEXICO

Health Facility Licensing and Certification Bureau  
Health Services Division - Complaint Division/Hospice  
525 Camino De Los Marquez, Suite 2  
Santa Fe, New Mexico 87501

STATE OF NEW YORK

Office of Health and System Management  
Department of Health - Complaint Division/Hospice  
Tower Building, Empire State Plaza, Room 1441  
Albany, New York 12237

STATE OF NORTH CAROLINA

Licensure and Certification Section  
Department of Human Services  
Complaint Division/Hospice  
805 Biggs Street  
P.O. Box 29530  
Raleigh, North Carolina 27626

STATE OF NORTH DAKOTA

Health Resources Section  
Division of Health Facilities  
Department of Health - Complaint Div./Hospice  
State Capitol, 600 East Boulevard Avenue  
Bismark, North Dakota 58505

STATE OF OHIO

Bureau of Medical Services  
Division of Licensing and Certification  
Department of Health - Complaint Division/Hospice  
246 North High Street  
P.O. Box 118  
Columbus, Ohio 43266

STATE OF OKLAHOMA

Licensure and Certification Division  
Department of Health -Complaint Division/Hospice  
1000 Northeast 10th Street  
P.O. Box 1299  
Oklahoma City, Oklahoma 73117

STATE OF OREGON

Department of Human Resources  
Human Resources Building - Complaint Division/Hospice  
500 Summer Street, NE, 2nd Floor  
Salem, Oregon 97310

STATE OF PENNSYLVANIA

Division of Health Care Facilities  
Bureau of Quality Assurance  
Department of Health - Complaint Division/Hospice  
P.O. Box 90  
Harrisburg, Pennsylvania 17108

STATE OF RHODE ISLAND

Division of Facilities Regulation  
Department of Health - Complaint Division/Hospice  
Cannon Building  
3 Capitol Hill, Room 306  
Providence, Rhode Island 02908

STATE OF SOUTH CAROLINA

Division of Certification  
Department of Health and Environmental Control  
Complaint Division/Hospice  
2600 Bull Street  
Columbia, South Carolina 29201

STATE OF SOUTH DAKOTA

Licensure and Certification  
Health Care Facilities, Department of Health  
Complaint Division/Hospice  
445 East Capitol Avenue  
Pierre, South Dakota 57501

STATE OF TENNESSEE

State Survey Agency, Health Care Facilities  
Department of Health, Complaint Division/Hospice  
Cordell Hull Building, Floor 1  
426 5th Avenue North  
Nashville, Tennessee 37247

STATE OF TEXAS  
Hospice Care Regulatory Division  
Department of Human Services - Complaint Division  
P.O. Box 149030  
Austin, Texas 78714

STATE OF UTAH  
Health Facility Licensure -Department of Health  
Complaint Division/Hospice  
P.O. Box 142853  
Salt Lake City, Utah 84114

STATE OF VERMONT  
Division of Licensing and Protection  
Department of Health - Complaint Div./Hospice  
103 South Main Street - Ladd Hall  
Waterbury, Vermont 05671

STATE OF VIRGINIA  
Office of Health Facilities Regulation  
Department of Health, Complaint Division/Hospice  
3600 Center Building, Suite 216  
Richmond, Virginia 23230

STATE OF WASHINGTON  
Department of Health and Social Services  
Health Facilities Licensure and Certification Department  
Complaint Division/Hospice  
P.O. Box 45600  
Olympia, Washington 98504

STATE OF WEST VIRGINIA  
Health Facility Licensure and Certification  
Department of Health. Complaint Division/Hospice  
Building 3, Room 550  
1900 Kanawha Boulevard, East  
Charleston, West Virginia 25305

STATE OF WISCONSIN

Bureau of Quality Assurance

Department of Health and Social Services, Complaint Division/Hospice

P.O. Box 309

Madison, Wisconsin 53701

STATE OF WYOMING

Office of Health Quality

Department of Health, Complaint Division/Hospice

First Bank Building, 8th Floor

Cheyenne, Wyoming 82002

## IMPORTANT RESOURCES

- ACCESSING THE FEDERAL LAWS GOVERNING HOSPICE
- ACCESSING YOUR STATE'S LAWS GOVERNING HOSPICE
- LIST OF ALL STATE WEBSITES

### ACCESSING THE FEDERAL LAWS GOVERNING HOSPICE, U.S. GOVERNMENT AND LEGAL INFORMATION SITES

The federal regulations governing hospice are presented within this book. For the latest version or revisions to these regulations, visit:

Government Printing Office  
United States Code of Federal Regulations  
[www.access.gpo.gov/nara/cfr/cfr-table-search.html](http://www.access.gpo.gov/nara/cfr/cfr-table-search.html)

For those who wish to directly access the entire federal hospice law for themselves. When you enter the site, search for the link to the Code of Federal Regulations for Hospice: cited as: 42 CFR 418.

Government Printing Office  
Proposed and recently adopted changes to the United States Code of Federal Regulations  
[www.access.gpo.gov/su\\_docs/aces/aces140.html](http://www.access.gpo.gov/su_docs/aces/aces140.html)

Search here to see if any changes were made recently to the laws governing hospice. When you enter the site, search for the link to the Code of Federal Regulations for Hospice: cited as: 42 CFR 418.

### INDIANA UNIVERSITY LAW LIBRARY

[www.law.indiana.edu/v-lib/](http://www.law.indiana.edu/v-lib/)

An excellent site to find laws on any topics. For State laws on hospice, click on the Browse by information type button, then click on State Government Servers. Scroll down to the State you live in and click on Administrative Code or Code of Regulations (names vary in each State). When you reach the Administrative Code or regulations for your State, use the Search button to find hospice. You'll see a listing of laws governing hospice in your State.

### CORNELL UNIVERSITY LAW LIBRARY

[www.secure.law.cornell.edu/topics/state\\_statutes.html#health](http://www.secure.law.cornell.edu/topics/state_statutes.html#health)

Provides text from State laws of many states in the U.S.

State laws governing hospice vary from State to State, and how they arrange the laws at their website also varies. You will need to click on the link for your State and then select or search for hospice (if hospice is available as a choice) or Regulations. After that you should be at the state laws on hospice for your area.

## U.S. Government and Legal Related Sites

### FIRSTGOV

<http://firstgov.gov>

An official U.S. government site that accesses all branches of federal government, its agencies, and has the ability to search by topic (not just U.S. agency), helps to find government services online. Also provides links to State and Local government web sites.

### AMERICAN HEALTH LAWYERS ASSOCIATION

[www.healthlawyers.org/home.htm](http://www.healthlawyers.org/home.htm)

A leading provider of education for attorneys dealing health care related issues, and through its Public Interest commitment, Health Lawyers gives back to society from its members' legal expertise. The tax-exempt association produces colloquium reports and other nonpartisan analyses that share Health Lawyers' expertise with policymakers, healthcare organizations, think tanks, academia, media, the public, and others. Health Lawyers also encourages its members to contribute to the public interest through pro bono legal work and other community service activities.

### FINDLAW.COM

[www.FindLaw.com](http://www.FindLaw.com)

FindLaw.com provides a wealth of information about the laws of our nation both State, federal and other and has lists of attorneys, search capability to find caselaw and discussions of the law in many specialties

### LAW.COM

[www.law.com](http://www.law.com)

Law.com offers comprehensive information and resources for attorneys, law students, law librarians and lawfirm management. It has a focus on serving professional attorneys, but also provides information for the general public. Also included are separate Law.com state websites for each state providing: local and state-wide news summaries and features; federal circuit and state court decisions (summarized and full text); highlights from law.com's national legal news; a state-specific legal practice guide.

#### THELAWENGINE.COM

[www.TheLawEngine.com/](http://www.TheLawEngine.com/)

One of the best legal/law search sites on the web with a large directory of law and legal-related sites.

#### USLAW.COM

[www.uslaw.com](http://www.uslaw.com)

USLaw.com provides legal information (for the public as well as for attorneys) on: crime and the courts, employment law, health and injury law, commercial law, real estate, family law, and much more. You can ask questions of lawyers, find attorneys, create documents and more.

### ACCESSING YOUR STATE'S LAWS GOVERNING HOSPICE

#### INDIANA UNIVERSITY LAW LIBRARY

[www.law.indiana.edu/v-lib/](http://www.law.indiana.edu/v-lib/)

An excellent site to find laws on any topics. For State laws on hospice, click on the Browse by information type button, then click on State Government Servers. Scroll down to the State you live in and click on Administrative Code or Code of Regulations (names vary in each State). When you reach the Administrative Code or regulations for your State, use the Search button to find hospice. You'll see a listing of laws governing hospice in your State.

#### INTERNET ACCESS TO RULES (STATE ADMINISTRATIVE CODES)

[www.nass.org/acr/acrdir.htm](http://www.nass.org/acr/acrdir.htm)

This complete listing is posted by the National Association of Secretaries of State: Administrative Codes and Registers Section. To find State administrative rules, codes or laws on any topics. For State laws on hospice, click on your State and the link to the word "code," then use the "Search" button to find "hospice." You'll see a listing of laws governing hospice in your State.

#### CORNELL UNIVERSITY LAW LIBRARY

[wwwsecure.law.cornell.edu/topics/state\\_statutes.html#health](http://wwwsecure.law.cornell.edu/topics/state_statutes.html#health)

Provides text from State laws of many states in the U.S.

State laws governing hospice vary from State to State, and how they arrange the laws at

their website also varies. You will need to click on the link for your State and then select or search for hospice (if hospice is available as a choice) or Regulations. After that you should be at the state laws on hospice for your area.

## ACCESSING YOUR STATE'S OWN INDIVIDUAL WEBSITE

*notE:* These U.S. individual state run websites are provided to help you get information from your individual State governments.

We do not recommend sending any complaint by e-mail or over the internet. We recommend sending a complaint by U.S. certified/return receipt mail. Mailig addresses for State licensing offices is provided within this book. With many states, there is more than one link listed here. A second link is usually the link for sites of interest to seniors or on aging. If you are looking for a State or local government site that is not the main state website, you can either go to the main State website listed below and search from there or try: "State and Local Government on the Net - A Piper Resources guide to government sponsored Internet sites. Their web address is: [www.piperinfo.com/state/index.cfm](http://www.piperinfo.com/state/index.cfm) Piper Resources provides a directory of government websites for each state with links to each branch of government, city and county government and more. An excellent resource!

Alabama

[www.state.al.us/](http://www.state.al.us/)

Alaska

[www.state.ak.us/](http://www.state.ak.us/)

[www.state.ak.us/local/akpages/ADMIN/dss/home.htm](http://www.state.ak.us/local/akpages/ADMIN/dss/home.htm) --Senior Site

Arizona

[www.state.az.us/](http://www.state.az.us/)

Arkansas

[www.state.ar.us/](http://www.state.ar.us/) Arkansas

[www.state.ar.us/dhs/aging/](http://www.state.ar.us/dhs/aging/) --Aging Site

#### California

[http://www.ca.gov/state/portal/myca\\_homepage.jsp](http://www.ca.gov/state/portal/myca_homepage.jsp)

[www.aging.state.ca.us/](http://www.aging.state.ca.us/) --Senior Site

#### Colorado

[www.state.co.us/](http://www.state.co.us/)

[www.cdhs.state.co.us/oss/aas/index.html](http://www.cdhs.state.co.us/oss/aas/index.html) --Aging Site

#### Connecticut

[www.state.ct.us/index.asp](http://www.state.ct.us/index.asp)

[www.dss.state.ct.us/](http://www.dss.state.ct.us/) --Aging Site

#### Delaware

[www.state.de.us/](http://www.state.de.us/)

<http://www.dsaapd.com> --Aging Site

#### District of Columbia

[www.ci.washington.dc.us/index.html](http://www.ci.washington.dc.us/index.html)

[www.ci.washington.dc.us/agencylist\\_0.html](http://www.ci.washington.dc.us/agencylist_0.html) --Aging Site

#### Florida

[www.state.fl.us/](http://www.state.fl.us/)

<http://fcn.state.fl.us/doea/doea.html> --Elder Site

#### Georgia

[www.state.ga.us/](http://www.state.ga.us/)

[www2.state.ga.us/Departments/DHR/aging.html](http://www2.state.ga.us/Departments/DHR/aging.html) --Aging Site

#### Guam

<http://ns.gov.gu/>

<http://mail.admin.gov.gu/pubhealth/index.html> --Seniors Page

#### Hawaii

[www.hawaii.gov/](http://www.hawaii.gov/)  
[www.maui.net/~cristan/index.html](http://www.maui.net/~cristan/index.html) --Aging Site

Idaho  
[www2.state.id.us/](http://www2.state.id.us/)  
[www.state.id.us/icoa/](http://www.state.id.us/icoa/) --Aging Site

Illinois  
[www.state.il.us/](http://www.state.il.us/)  
[www.state.il.us/aging/](http://www.state.il.us/aging/) --Aging Site

Indiana  
[www.ai.org/](http://www.ai.org/)  
[www.ai.org/fssa/HTML/PROGRAMS/2b.html](http://www.ai.org/fssa/HTML/PROGRAMS/2b.html) --Aging Site

Iowa  
[www.state.ia.us/](http://www.state.ia.us/)  
[www.sos.state.ia.us/register/r4/r4eldaf.htm](http://www.sos.state.ia.us/register/r4/r4eldaf.htm) --Aging Site

Kansas  
[www.ink.org/](http://www.ink.org/)  
[www.k4s.org/kdoa/default.htm](http://www.k4s.org/kdoa/default.htm) --Aging Site

Kentucky  
[www.state.ky.us/](http://www.state.ky.us/)  
<http://cfc-chs.chr.state.ky.us/aging.htm> --Aging Site

Louisiana  
[www.state.la.us/](http://www.state.la.us/)  
[www.gov.state.la.us/depts/elderly.htm](http://www.gov.state.la.us/depts/elderly.htm) --Elderly Affairs Page

Maine  
[www.state.me.us/](http://www.state.me.us/)  
[www.state.me.us/dhs/beas/](http://www.state.me.us/dhs/beas/) --Elder Site

## Maryland

[www.mdarchives.state.md.us/msa/homepage/html/mdgov.html](http://www.mdarchives.state.md.us/msa/homepage/html/mdgov.html)

[www.mec.state.md.us/](http://www.mec.state.md.us/) --Electronic Capital

[www.inform.umd.edu:8080/UMS+State/MD\\_Resources/OOA/index.html](http://www.inform.umd.edu:8080/UMS+State/MD_Resources/OOA/index.html) --Aging

## Massachusetts

[www.state.ma.us/](http://www.state.ma.us/)

[www.state.ma.us/src.htm](http://www.state.ma.us/src.htm) --Senior Site

[www.state.ma.us/elder/](http://www.state.ma.us/elder/) --Elder Affairs

## Michigan

[www.migov.state.mi.us/](http://www.migov.state.mi.us/)

[www.mdch.state.mi.us/mass/masshome.html](http://www.mdch.state.mi.us/mass/masshome.html) --Aging Site

## Minnesota

[www.state.mn.us/](http://www.state.mn.us/)

[www.mes.umn.edu/Accessmn/](http://www.mes.umn.edu/Accessmn/) --Access Minnesota

[www.dhs.state.mn.us/aging/default.htm](http://www.dhs.state.mn.us/aging/default.htm) --Aging Site

## Mississippi

[www.state.ms.us/](http://www.state.ms.us/)

[www.mdhs.state.ms.us/aas.html](http://www.mdhs.state.ms.us/aas.html) --Aging Site

## Missouri

[www.state.mo.us/](http://www.state.mo.us/)

[www.dss.state.mo.us/da/da.htm](http://www.dss.state.mo.us/da/da.htm) --Aging Site

## Montana

[www.state.mt.us/](http://www.state.mt.us/)

[www.dphhs.state.mt.us/sltc/](http://www.dphhs.state.mt.us/sltc/) --Senior Site

<http://vhsp.dphhs.state.mt.us> --Virtual Pavillion

## Nebraska

[www.state.ne.us/](http://www.state.ne.us/)

[www.hhs.state.ne.us/ags/agsindex.htm](http://www.hhs.state.ne.us/ags/agsindex.htm) --Aging Site

Nevada

[www.state.nv.us/](http://www.state.nv.us/)

[www.state.nv.us/hr/aging/](http://www.state.nv.us/hr/aging/) --Aging Site

New Hampshire

[www.state.nh.us/](http://www.state.nh.us/)

[www.state.nh.us/dhhs/ofs/ofscstlc.htm](http://www.state.nh.us/dhhs/ofs/ofscstlc.htm) --Aging Site

New Jersey

[www.state.nj.us/](http://www.state.nj.us/)

[www.state.nj.us/health/seniors.htm](http://www.state.nj.us/health/seniors.htm) --Senior Site

[www.state.nj.us/health/senior/sraffair.htm](http://www.state.nj.us/health/senior/sraffair.htm) --Senior Site 2

New Mexico

[www.state.nm.us/](http://www.state.nm.us/)

[www.nmaging.state.nm.us/](http://www.nmaging.state.nm.us/) --Aging Site

New York

[www.state.ny.us/](http://www.state.ny.us/)

[www.aging.state.ny.us/nysofa/](http://www.aging.state.ny.us/nysofa/) --Aging Site

North Carolina

[www.sips.state.nc.us/](http://www.sips.state.nc.us/)

[www.cse.state.nc.us/DHR/DOA/home.htm](http://www.cse.state.nc.us/DHR/DOA/home.htm) --Aging Site

North Dakota

[www.state.nd.us/](http://www.state.nd.us/)

Ohio

[www.state.oh.us/](http://www.state.oh.us/)

[www.state.oh.us/age/home.htm](http://www.state.oh.us/age/home.htm) --Aging Site

Oklahoma

[www.state.ok.us/](http://www.state.ok.us/)

#### Oregon

[www.state.or.us/](http://www.state.or.us/)

[www.sdsd.hr.state.or.us/](http://www.sdsd.hr.state.or.us/) --Senior Site

#### Pennsylvania

[www.state.pa.us/](http://www.state.pa.us/)

[www.state.pa.us/PA\\_Exec/Aging/overview.html](http://www.state.pa.us/PA_Exec/Aging/overview.html) --Aging Site

#### Puerto Rico

<http://fortaleza.govpr.org/>

#### Rhode Island

[www.state.ri.us/](http://www.state.ri.us/)

[www.state.ri.us/manual/data/queries/stdept\\_.idc?id=23](http://www.state.ri.us/manual/data/queries/stdept_.idc?id=23) --Senior Site:

#### South Carolina

[www.state.sc.us/](http://www.state.sc.us/)

#### South Dakota

[www.state.sd.us/](http://www.state.sd.us/)

[www.state.sd.us/state/executive/social/ASA/asa.htm](http://www.state.sd.us/state/executive/social/ASA/asa.htm) --Senior Site:

#### Tennessee

[www.state.tn.us/](http://www.state.tn.us/)

#### Texas

[www.state.texas.us/](http://www.state.texas.us/)

[www.tdoa.state.tx.us/](http://www.tdoa.state.tx.us/) --Aging Site

#### Utah

[www.state.ut.us/](http://www.state.ut.us/)

[www.hsdaas.state.ut.us/](http://www.hsdaas.state.ut.us/) --Aging Site

Vermont

<http://www.state.vt.us/>

[www.dad.state.vt.us/](http://www.dad.state.vt.us/) --Aging Site

Virginia

[www.state.va.us/](http://www.state.va.us/)

[www.aging.state.va.us/](http://www.aging.state.va.us/) --Aging Site

Washington

<http://access.wa.gov/>

[www.aasa.dshs.wa.gov/](http://www.aasa.dshs.wa.gov/) --Aging Site

West Virginia

[www.state.wv.us/](http://www.state.wv.us/)

Wisconsin

[www.wisconsin.gov/state/home](http://www.wisconsin.gov/state/home)

[www.dhfs.state.wi.us/aging/index.htm](http://www.dhfs.state.wi.us/aging/index.htm) --Aging Site

Wyoming

[www.state.wy.us/state/welcome.html](http://www.state.wy.us/state/welcome.html)

<http://wdhfs.state.wy.us/WDH/default.htm> --Senior Site

## **RESOURCES TO REPORT FRAUD IN HOSPICE**

To report fraudulent practices by hospices in your area, contact the U.S. Department of Health and Human Services - Office of Inspector General "Fraud Hotline" at its website

for a direct e-mail link (see below) or call Tel. No. 1-800-447-8477 (800-HHS-TIPS). You can also call the regional office for your area (see below).

We recommend that you put your complaint in writing, including specific information about the nature of your complaint, with dates and names, and then mail it by certified/return receipt U.S. mail to the regional office that covers your area. You should also contact your local U.S. Attorney's Office (part of the U.S. Dept. of Justice) to report violations of the law and fraud.

Putting an end to health care fraud and hospice fraud is a responsibility of all U.S. citizens. We do not recommend reporting fraud to your state's Department of Public Health or "Bureau of Health Systems." If your hospice care is paid for by private commercial insurance, HMO or managed care, then report fraud to your private insurance company's fraud department and your state's Attorney General's office.

State Health Dept. agencies are appropriate for reporting violations of standards of care, but the U.S. government agencies listed below are the appropriate agencies to notify when healthcare fraud occurs and Medicare or Medicaid is involved. When any hospice or other agency signs on patients and bills Medicare, Medicaid, or private insurers without providing full service to the patients, families and care givers, and the bereaved, fraud is occurring. If a hospice bills you directly for hospice services related to the terminal illness, even though the patient has coverage under Medicare, Medicaid or private insurance, fraudulent double-billing may be occurring. Do not be exploited. Report it. Help stop hospice fraud!

The greatest enemy of quality hospice care, and hospice in general, are "rogue" hospices and their "clever" administrators, who operate for their own enrichment and violate the very mission of hospice. They may be well-established and large; they may routinely have long articles about their hospice services in the newspapers, praising the wonderful services they provide to the dying. Beware, these rogue hospices violate the rights of numerous patients and thereby, they give hospice a bad "word of mouth" reputation which rarely gets explored in the news media.

And those hospices which run an honest operation struggle to get coverage in the media for their excellent work.

Please take into consideration that large hospices pay large amounts for advertising in the press, and so newspapers reward them with wonderful reviews (one hand wipes the other). Fortunately, there are many hospices which provide excellent care, and without a doubt, the hospice staff you will encounter are mostly extremely dedicated to the hospice mission.

U.S. DEPT. OF HEALTH AND HUMAN SERVICES  
OFFICE OF INSPECTOR GENERAL'S FRAUD HOTLINE

[www.hhs.gov/progorg/oig/](http://www.hhs.gov/progorg/oig/)

You can directly e-mail a complaint to the Office of Inspector General from their website or e-mail them at: [Htips@os.dhhs.gov](mailto:Htips@os.dhhs.gov) 1-800-447-8477 (1-800-HHS-TIPS)

(If you write to the national office, it may take several months for them to get back to you; you will get a faster response if you call your regional Office of Investigations of the Office of Inspector General. For your convenience we list the regional phone numbers here:

Boston - MA, VT, NH, ME, RI, CT 617-565-2660

New York - NY, NJ, PR, VI 212-264-1691

Philadelphia - PA, MD, DE, WV, VA, DC 215-861-4586

Atlanta - GA, KY, NC, SC, FL, TN, AL, MS 404-562-7603

Chicago - IL, MN, WI, MI, IN, OH, IA, MO 312-353-2740

Dallas - TX, NM, OK, AR, LA, CO, UT, WY, MT, ND, SD, NE, KS 214-767-8406

Los Angeles - AZ, NV, So. CA 714-246-8302

San Francisco - No. CA, AK, HI, OR, ID, WA 415-975-4570

We recommend that you call these regional offices and get the direct mailing address for the special agent there with whom you speak ... and then, always put your complaint in writing.)

U.S. ATTORNEY'S OFFICE

[www.usdoj.gov/02organizations/02\\_1.html](http://www.usdoj.gov/02organizations/02_1.html)

U.S. Department of Justice

Washington, D.C. 20530-0001

The U.S. Attorney's Office can be found at a listing of branches of the Dept. of Justice website. The U.S. Attorneys office investigates and prosecutes federal crimes. Click on the link to the "U.S. Attorneys Listing" and then scroll down the page to locate the listing for your State or region.

It is wise to send a complaint to the U.S. Attorney's office when you are certain that health care fraud or a wrongful death has occurred. For example, if a patient was given medications which the patient had refused to take, and was given a medication which may have been intended to cause death before the patient would have naturally died, an involuntary death or involuntary euthanasia may have occurred (plainly speaking "murder").

These serious violations of patient rights need to be investigated by professional criminal investigators. Just because a patient is terminally ill does not give any physician, nurse or health care agency the right to put someone to death using medications against the patient's will. If you have any questions, you can call the U.S. Attorney and set up an appointment to meet with them. You can also find the local U.S. attorney's office in your city directory under the category of: "United States Government - United States Attorney."

## A WORD TO HEALTH CARE PROFESSIONALS

While the business of health care continues to struggle to find ways to meet the needs of all health care recipients, all of us in the health care industry must realize that not providing appropriate care is not the answer, even though many agencies choose this line of "increasing profits" as a "quick fix" to their financial concerns. The question is no longer: "which hospital, agency or institution would dare to violate such basic patient rights as the right to essential services delivered according to the standards of care in the industry?" ... the question now is, "which hospital, agency or institution is the exception and actually is providing essential services according to the standards of care in the industry?"

Saving money by under-staffing, under-medicating, under-serving patients, "looking the other way" (to maintain physician referral sources), and not informing patients of all treatment options or services has become quite common. While one institution may not violate all standards, all the time, in all locations or departments, it is likely to violate one or more standard in a department or location, consistently from time-to-time! And even more alarming, the administrators of our hospitals, agencies and institutions are consciously choosing to create situations which they know will result in the violations of the standards of care.

Intentional and knowing violations of the standards of care are absolutely unacceptable! If health care providers such as physicians, nurses, social workers and therapists do *not* speak up in order to assure quality care, and do *not* force a halt to the changes now occurring, there will no longer be a health care system as we know it. In almost any setting health care professionals will not be able to practice consistently on an ethical basis and still retain their jobs. This means that there will be times when each health care professional will be confronted with a situation in which they will be forced to "look the other way" or compromise the standards of practice for their profession. And if they do not, they will no longer have a job.

In fact, the current reality of health care often punishes the ethically concerned practitioner while rewarding those who look the other way and work the system, for their own benefit. There have been many journal articles detailing the ineffectiveness of many professionals' efforts to improve the quality of care at their place of employment. Some staff may report problems following the chain of command (as we're all told we're "supposed to do") and find no action taken by executive management to correct the problem. In those cases where management does nothing to correct a glaring problem, the problem is most likely consciously known and accepted by the executive management as

a "necessary" result of administrative decisions taken by the corporate Board of Directors to bolster profit margins or please shareholders (if a for-profit corporation).

Betraying the trust of our patients in order to personally prosper is a despicable violation of everything our licenses stand for. Patients and families put their trust in the health care professionals and deserve our very best.

If you have real ethical dilemmas at your employment, ask yourself why you entered this profession; review your profession's code of conduct, review your legal responsibilities to your patients, and be willing to take a stand for your patient's rights. However, take a stand intelligently and protect yourself and your license as well. While some professionals simply quit and "move on" to another facility, the current reality is such that you may simply be changing one problem employer for another. Health care agencies are not hesitant to violate standards of care that involve you!

If you do try to attempt to correct the situation, you may find it helpful to follow some of the following general guidelines: Get legal advice if you believe there is some illegal activity going on. (Actually going to the trouble of paying for, and asking an attorney before you do anything may actually be the least expensive path.) Even though attorneys are expensive, paying for an hour or two of advice can save you much heartache ... (we are not offering advice on lawsuits). You need to know what your rights as an employee are and what your employer might do (regardless of what your "legal rights" are). Employers often circumvent "legal" protections to employees by making other "arrangements." They can try to find ways of creating "trouble" for you or making it more desirable for you to resign. You will have to decide whether or not you wish to actually do anything. What you decide will say much about your own character and strength of convictions.

If you do decide to work on correcting a situation at your workplace, document exactly what the situation really is: what the patient expressed, what the family may have stated, what the patient's need is, what your assessment is, what others stated and/or did, what supervisors instructed you to do ... all of these are important aspects of protecting yourself and your license. Remember that the chart is the record, legally, of what happened or did not happen. If you do not chart your concerns and do not tell others, you have nothing to support your perception of the situation. Write down your own notes about your concerns and keep a dated and signed copy at home.

Make sure to communicate your concerns to other co-workers. If you do not tell anyone else except your supervisor, you may find yourself illegally terminated for some "trumped up" charge that has no bearing in reality. If you make your concerns known in front of many co-workers, retaliation will be less likely to happen and you will be more easily able to prove any retaliation, if it occurs. If you have a union, speak with your

representative. If not, speak with your professional organization's ethics committee and legal advisors. Make your assessment known to your supervisor.

Whether you are a nurse, physician or social worker, there will be times that the "institution" may try to exert influence on you, against your professional judgment about what is the correct course of conduct. We all need to be more active in advocating for patients' rights and staff's rights as well.

If you observe health care fraud or other types of criminal activity, you are legally obligated to report this to the U.S. Office of the Inspector General and other agencies. Although you can make a report by phone, it is recommended that you make any report in writing, by certified return-receipt U.S. mail. Always keep copies of any documentation you have access to which can provide evidence about the violations occurring.

While you cannot keep charts, you can keep correspondence or postings, e-mail or announcements. You can make anonymous and confidential reports if you are afraid of retaliation, but you'll need to include enough information to adequately describe exactly what is going on so that the agency can correct the problem. Do *not* believe "advice" from fearful co-workers who tell you to "keep quiet or they will shut down the facility." It is highly unlikely that reporting criminal activity is going to threaten your employer with being "shut down." Rarely do agencies get totally shut down, however, white-collar criminals do go to jail for their crimes ... and they are criminals! As a citizen and licensed professional, and for the patient's welfare, do the right thing and report to the federal government.

A word of caution is also in order here. If you report to your state's Division of Licensing and Certification, do not expect confidentiality and do not expect the state to always "do the right thing." There is a lot of administrative corruption in local state governments and the political connections may be unbelievable until you have tried to make a complaint. Any health care agency that is fairly large and respected in your community is going to have Board members and others who "know" somebody at the state level. Sometimes the state will "look the other way" to protect political "friends." It is a case of the business "network" protecting its own. Employees are not part of the political "network." Employees who violate the rules can get nailed to the wall, but employers rarely do, unless they're not "connected." This is not the time to be naive!

# **PROTECTING YOURSELF, YOUR LICENSE, YOUR FAMILY, AND YOUR FINANCIAL & JOB SECURITY WHEN DEALING WITH FRAUD AT YOUR EMPLOYER**

If you work in the health care field, in hospice or elsewhere, eventually you are likely to observe behavior or practices that are not in accordance with the standards of care. In fact, you are likely to observe some form of health care fraud, on a minor or major basis. What you do in response to that fraud can have significant impact upon your life, your professional status, future job prospects and financial well-being. Making the wrong decision about fraud in your workplace can cost you your job, your license and even end up putting you in jail; health care fraud is a felony criminal violation! Do not think employers will sit while you complain about their intentional, conscious wrongdoing!

All throughout your professional training, you have been instructed that if you observe a problem at your job, you should work "within the system" and "report it to your supervisor." Then, if you do not get a proper resolution of the problem, you have been trained to report to the next higher supervisor/manager, and on up the "chain of command." With the "business" approach to health care dominating more and more, many health care agencies have lost their concern for the standards of care, and respect for patients' rights has been thrown to the wind. If the upper management at the agency you work for is at the root of the problem and has been intentionally violating the standards of care, you might be very effectively destroying your own employment at that agency, as well as at other agencies, if you protest too loudly. You will be labeled "troublemaker, disgruntled employee" after they find a reason to fire you.

Of course, terminating employees can cost the agency, so it is likely they will harass you or irritate you enough to get you to resign ... so they can avoid paying you unemployment benefits. It is no secret that employers will put you under intense scrutiny to "find" something with which to complain about you, and "write you up" for your "inferior" performance. This process will be repeated, with many emotionally draining confrontations with lower management personnel who will have been instructed to berate you for your performance, find fault and get you to resign.

Some managers will call you into a "private" behind-closed-doors meeting with one or probably two managers especially "gifted" at degrading you, mocking your skills, criticizing you for any weakness or fault they can find, and even yelling at you. Do not stand for it. This is harassment: retaliation! If you stay at your employment, even after they begin to harass you, you are working up a thick file of documentation which will tell any new employer how "bad" you are, and how "poor" your performance is. You may have difficulty getting a job. Nurses have experienced forms of retaliation as "reward" for

being professional, ethical and trying to maintain integrity and why so many "burn out" and leave the field.

You may think that employers are not "allowed" to tell any prospective employer what is in your file, that they can only tell when you worked there, how long; you will be very mistaken in your beliefs. What is to stop human resources personnel at different employers from speaking with one another, especially if they agree to "keep quiet" about retaliating against you. Do you think that human resources personnel from different agencies might associate with one another, or belong to the same "association" of human resources professionals???

Nothing is physically stopping employers from speaking on the phone confidentially to tell the new employer that you are a "troublemaker." If you can imagine any form of retaliation, you can be sure that your employer will use it if necessary, if the employer is really corrupt. (How would you know if they did go behind the scenes and slander you in private? How would you ever know? They used to call it "blackballing," and it still exists!)

If you observe problems at your place of work, yes, certainly, voice your opinion and see if appropriate changes are made. But once you are convinced that no meaningful change is going to occur and it is the agency itself that intends to commit these violations of the standards, perhaps for financial gain, you need to look for another job and get out of there as fast as you can! This does not mean you no longer have an obligation to report the violations. Just protect yourself and your family as well as reporting the fraud to the federal government. You can always report fraud after you have a new job.

On the other hand, you could stay at your current employment and report the fraud anonymously, but sometimes the employer will figure out that you are the one who reported them. If they do, again, they will find a way to get you to resign or to force you out, if they do not outright terminate you. Agencies that commit fraud always have "sweet-talking" administrators who can talk out of both sides of their mouths and say anything necessary to make the agency look "professional" and "clean" from the legal angles. However, when the U.S. Office of Inspector General or U.S. Attorney's Office performs their investigations, they will find the wrongdoing and prosecute the white-collar criminals involved. Health care fraud must stop. If it doesn't, health care as we know it will no longer exist, and professional services in your field will no longer be "professional." The patients will no longer be able to get decent services and will suffer terribly. All of us will be "slaves of the system," unable to speak up or advocate at all for our patients.

Be smart. Protect yourself, your family, your job and protect the profession. Every professional journal in your field advises that if you are in a situation in which you must violate the law or standards governing your license, and you stay, you are responsible for your actions. The only course of action which allows you to retain your integrity is for you to get another job, however unpleasant or difficult that may be. Nobody wishes to change their employment if they feel comfortable at their employment. But remember, you will not feel comfortable at your employment if you stay at an agency that is committing fraud ... at least, you will not feel comfortable if you have any integrity.

If you stay at the agency, you run the risk of yourself being found guilty of some federal or state law, or of being found guilty of violating your license, depending on the circumstances in your situation. If you do things which you know are "wrong" or illegal, you could go to jail for many years. There have been nurses used as scapegoats for the agencies who instituted the illegal activities. Do not think for an instant that the agency would not sacrifice you in order to protect its own interests! Health care agencies do it every day! They "nail" the nurse or doctor to the wall, while saving their own skin. If they can, they will blame it on you. You need to voice your objections, document your objections in whatever way you can, get out and report the criminal activity to the authorities.

What if you have already "made waves" at your workplace, and the employer considers you a "troublemaker" already? What if you are looking for a job and having trouble getting another job? We suggest that you not be "picky" about the work you take, and avoid moving directly to a job at a similar employer. Take the positions that are available from employers willing to hire you and get on with your life. You may find success by changing to home health care/private duty for a year or so. It may be helpful to consider part-time or contingent work for two or three employers at the same time. You may need to work for these two or three employers on this part-time basis for a year or so, until the fraudulent employer (who is trying to retaliate against you) is "down the list" on your resume, and can no longer "blackball" you. Do not think they will not do it. Be wise.

The quickest way to get your life back together after a miserable experience with a corrupt employer is not always to get the "perfect" job that you always wanted. If you can get it, fine ... but if you are having an unusually difficult time obtaining new employment, assume that your previous employer is retaliating against you (most likely in a way that you could never prove in court) and take some "stepping-stone" jobs temporarily. You need to be practical and understand that your former employer is actively trying to hurt your chances for new employment in the health care field. A war is occurring in the health care field, and it is being waged by corrupt white collar criminal administrators against health care professionals who dare to speak up against the outrageous violations of patients rights and standards of care.

Taking a job as a stepping stone to putting your former employer behind you may be the smartest thing you ever did, to preserve your financial well-being, your emotional well-being and your professional reputation. The "blackballing" of employees who "cause trouble" still occurs, only employers are very "slick" and very "clever" in how they go about avoiding getting caught in the act. Any employer who intentionally violates the law to commit health care fraud will not hesitate to retaliate against an employee who makes waves, complains and reports their violations. They hire lawyers and consultants who tell them how to deal with "those types of employees" without getting into legal trouble.

# HOSPICE STANDARDS OF CARE

The most important federal and State law governing hospice requires that hospices provide all services necessary to meet the needs of the terminally ill patient enrolled in the licensed hospice. [\(19\)](#) This law requires services to be available as needed seven (7) days a week, twenty-four hours a day. The immediate problem most families might encounter is their lack of information about what actually is required under the law. If you do not know what is required, you do not know what services you are entitled to receive!

If you do not know what the law says, you can easily be hoodwinked by those who might attempt to short-change you and not provide certain services. As difficult as it may be to imagine that those caring for your loved one might not provide everything needed for your loved one, certain hospices do routinely violate their patients' rights to care, for their own financial benefit. This can easily be verified by requesting a copy of the State survey/inspection summary reports of hospices which violate the laws and by requesting copies of summary reports of inspections conducted in response to complaints against the hospice. If you do request a copy of such survey summary reports, it is very important that you specify that you are requesting the information under the Freedom of Information Act (which requires the State to release this information). This is the kind of information the hospice will never want you to see or to be aware of, because it can be extremely revealing about the actual problems occurring at a hospice.

Because hospices are reimbursed on a per diem (per day of enrollment in the program) the hospice benefits financially when it provides fewer services and loses financially when it provides more services. The daily reimbursement does not increase when more services are provided; the daily reimbursement does not decrease when fewer services are provided. This is fertile ground for health care fraud, wouldn't you say? The federal and State laws are supposedly designed to assure that the hospices provide you with all the care needed for the care of your loved one. However, a major focus of the law is to assure that the federal and State governments get what they are paying for. The government does not like to hand out money without getting services in return. In those cases where services are not provided, even though the hospice is billing the government for full services, fraud is occurring, which must be reported to the U.S. Office of the Inspector General and the U. S. Attorney's Office for your local area.

## THE LAWS GOVERNING HOSPICE (THE UNIFORM STANDARDS OF CARE)

You can rest assured that the Federal and State governments have specific standards of care written into law to protect you and your loved one. Federally recognized hospice care in the United States began with implementation of parts of the Social Security Act (including Sections 1102, 1861 and 1871/42 U.S.C. 1302 and 1395hh and other sections). Regulations governing the conditions under which hospice agencies may participate in the Medicare hospice benefit are spelled out in the US Code of Federal Regulations originally published in the Federal Register.

Hospices must meet these "Conditions of Participation" to become licensed and certified by state regulators and to be allowed by HCFA to continue to participate in the Medicare hospice program. Without certification as meeting these standards, hospices cannot receive reimbursement for enrolling patients in their program. "Certification" does not necessarily mean that a hospice actually will comply with all the standards in any one patient's case; it simply means that after the last inspection, the regulators decided to certify the hospice as meeting the standards. There are many reasons why state inspectors may not find all violations occurring in any one particular hospice agency's program of services.

Hospice administrators are extremely aware of what the regulations are, however hospice staff are not always fully informed about all the details of the standards of care. In the case of rogue hospices which choose to consciously violate the standards for their own financial benefit, you can be sure that most of the hospice staff do not really understand all the laws governing hospice (however well-motivated hospice staff may be).

The rogue hospice agencies take a calculated risk when they violate the standards, basically betting that these violations will not be discovered by inspectors, or that even if discovered, they can take actions to avoid being decertified. Their actions clearly show that they believe that they will, in the long run, benefit more financially by violating the standards than by complying with the standards. However, if you are fully informed about your rights, you can protect your loved one and yourself from exploitation and easily require the hospice to provide all the care needed for your loved one.

The Federal law can be found in any metropolitan public library in the books containing the Code of Federal Regulations (See 42 CFR ch iv. Part 418 which governs hospice). Ask your reference librarian for assistance. Federal laws governing hospice may also be directly found on the U.S. government printing office's website at:  
[www.access.gpo.gov/nara/cfr/cfr-table-search.html](http://www.access.gpo.gov/nara/cfr/cfr-table-search.html)

State laws governing hospice can be found by searching at your own state websites. (See section on links to other sites for your state's website). Then look under "Administrative Law - Hospice", "Administrative Code - Hospice" or "Regulations - Hospice", ... or you can search at:

Indiana University Law Library  
[www.law.indiana.edu/v-lib](http://www.law.indiana.edu/v-lib)

An excellent site to find laws on any topics. For State laws on hospice, click on the "Browse by information type" button, then click on "State Government Servers." Scroll down to the State you live in and click on "Administrative Code" or "Code of Regulations" (names vary in each State). When you reach the Administrative Code or regulations for your State, use the "Search" button to find "hospice." You'll see a listing of laws governing hospice in your State.

Cornell University Law Library's website  
[wwwsecure.law.cornell.edu/topics/state\\_statutes.html#health](http://wwwsecure.law.cornell.edu/topics/state_statutes.html#health)  
You can find links to your State's laws on hospice care at this site ... an excellent resource!

The federal law governing hospice is printed in full at the end of this text. It can also be found on the internet (for the very latest up-to-date revisions).

To access these laws, you will have to find the federal government printing office at: <http://www.access.gpo.gov/nara/cfr/cfr-table-search.html> Once at the Government Printing Office website, click on the link for the U.S. Code of Federal Regulations, select Title 42, and then search for part 418 "Hospice" in the "Search" box and click. You will then be taken to the Federal Law on hospice at 42 CFR ch. iv. Part 418.

Newly proposed and accessed laws can be found at:  
[www.access.gpo.gov/su-docs/aces/aces140.html](http://www.access.gpo.gov/su-docs/aces/aces140.html).

Note: links on the world wide web are quickly changing. Although we do not expect the links mentioned in this book to change any time soon. If you do not find the information or website referred to in this book, please check our website where we may have updated the link. If there is no update on the website, please e-mail us to notify us about the link in question and we will try to assist you.

## **PHYSICIANS, NURSES AND OTHER STAFF: ADVOCATES FOR YOUR WELFARE?**

When any individual seeks health care, he expects that the physicians, nurses, social workers and other professionals will provide the very best of care in accordance with the most modern standards in the health care industry. Whether it is surgery or medical management of a disease, the expectation never changes. Most people trust their physician and nurses who care for them, their counselors and therapists. Health care professionals are quite often perceived as quite dedicated individuals who do their very best in caring for their patients.

Hospice is no different from any other aspect of the health care industry in terms of the degree of competence and integrity that is expected by the general public. However, hospice patients and their families are less likely to know when they're being exploited, because it is less likely that they would know about the standards of care for end-of-life care. Even if they do know the standards, hospice patients and their families are less likely to complain, because of their fatigue, the overwhelming intensity of involvement in caring for their loved one (often around the clock), and their intense grief.

Physicians, nurses, social workers, professional counselors and therapists are licensed in each state to provide health care services. Each state has standards of care for all health care professionals, and each professional organization has published its own code of ethics and standards of care. Any licensed health care professional has a duty under the law to maintain professional competence, abide by the code of ethics, and actually provide care that meets the standards of care. Most health care professionals take pride in being competent at their work, staying up-to-date, and doing the best for their patient. There is a natural bond between health care professionals and their patients. Many will fight for their patients to protect the patients' interests. That is what patients expect and what they often receive.

However, with the changes in the health care industry, constantly rising costs of providing services, and stiff competition among health care agencies, hospitals, nursing homes, and hospices, the business of running a health care agency or hospice has taken over in terms of controlling what directives management gives to its staff. No longer can you safely assume that the agency or hospice will necessarily do what is right or according to the standard of care. Cutting corners has become commonplace in health care. This places terrible strain on the health care staff, who are pulled in mutually exclusive directions by their different obligations under their license and to their employer.

Health care professionals' first obligation under the law and their license is to the patient: to abide by the Code of Ethics for their profession, maintain professional competence and actually provide the care that meets the standards of care for their line of work. The second obligation health care professionals may feel heavily weighing on their shoulders is to their employer; if the employer directs the health care professional to violate the standards of care (in order to save the employer money), he or she must choose between pleasing the employer (and keeping a job) and doing what is right for the patient. To make matters even more complicated, non-physician staff have a third obligation: to follow the physician's orders.

While ideally all three obligations coincide in agreeing on the patient's best interests, sometimes they all disagree, and nurses, social workers and others must choose which obligation to honor. If the employer requires care to be provided one way, and the physician disagrees and orders differently, for example, what is the nurse to do? If the doctor fails to order needed medications, but the agency has its own standards of care, the nurse must challenge the doctor's orders by either directly confronting the physician or going through supervisors who may negotiate for her and work out a reasonable solution. Sometimes the patient's best interests are not met in the health care setting, but the obligations of their licenses are closest to the hearts of the health care professionals, and they will try to advocate for your welfare.

Physicians, nurses, social workers and others routinely confront these conflicting obligations and try to find a compromise between the three points of view that is acceptable to all obligations. However, when the policy of the employer is clearly in violation of the standards, or when the physician fails to order what is best for the patient, the health care professional must choose between right and wrong. There is no middle ground when health care fraud is directed and intentionally committed at the administrative level, or when a patient's well being is threatened by physicians who do not meet the standards of care for medical practice.

Hospice is fertile ground for health care fraud. There are many ways of exploiting the patients, families and the reimbursement source, whether Medicare, Medicaid, private insurance, or the patients and families own money. Federal investigators have struggled with attempting to stop the flood of health care fraud violations occurring. When the U.S. Office of Inspector General started its Fraud Hotline, they were flooded with thousands of calls about health care fraud. Career criminals have even been quoted as saying that it was easier to make fortunes defrauding Medicare than through the sales of illegal drugs.

If you are receiving care from health care professionals, you can expect that most of them are very dedicated and honest individuals. That does not mean that fraud might not occur. Some honest individuals do not have the courage to fight the system and simply decide to

choose to ignore violations which are occurring - - trying to stay uninvolved and just do their jobs. The financial incentive to the agency/health care institution is to commit fraud in order to bolster their bottom line. The financial incentive to the health care professional to keep quiet arises out of their need to keep their paycheck coming to support their family. Challenging one's employer's policies is a sure method of becoming very unpopular at work. Management does not look favorably on employees who expose their white-collar crime! Even co-employees may avoid a health care professional who makes a complaint against the employer ... they simply do not want to have their own jobs threatened.

For the hospice patient and families, you can expect that some of the physicians, nurses, social workers or other staff will definitely speak up on your behalf if they think that improper decisions regarding health care are occurring. The best thing you can do to help these health care professionals is to listen closely to what they may say to you. Remember their comments if any problem arises, if you are having difficulty getting proper services. By listening to what some of the hospice staff may tell you, you can glean extremely important clues to what you should be receiving, but may not be receiving ... or you may learn of problems which you did not even know existed

Remember, if you do not know the standards in hospice, how can you know when you are being exploited? If you determine that any of the services you are receiving are inadequate or improper, your complaint directly made to the hospice management will be much more powerful than any complaint made by an employee. If you have questions about the care being provided, ask one of the staff with whom you seem to have a stronger, closer relationship and who you trust. If you are still unsure, you can contact other hospices, health care professionals you may know or call us at the Hospice Patients Alliance.

While all health care professionals are required to be advocates for the patients under their care, the reality is that some health care professionals choose to look the other way and keep quiet to save their own job. Health care fraud, under-serving patients and outright violations of standards of care does occur. You can help stop it from continuing by listening closely to the staff you meet, by learning as much as you can about the standards of care (that is one of the reasons for the Hospice Patients Alliance ... to help inform you and protect you), read the contracts and literature provided by the hospice, and be willing to ask probing questions of the hospice staff who work with you. Some hospice staff do not know the full meaning of the standards of care and have been misled by their hospice employers. If you have doubts about what you are told, look up the law for yourself in the Section on Federal Laws Governing Hospice: the Uniform Standards of Care. (We will be happy to explain the standards to you if you call.)

## STANDARDS OF CARE - MEDICAL

While most of us cannot know all the intricacies of medical science, all the extremely detailed research on the most up-to-date care, we can have a general understanding of the standards of care. Physicians are licensed in each state to practice medicine. While the standards of care vary for each specialty within medicine, each physician is required to maintain professional competence, to act honestly and with integrity, to fully inform patients about all treatment options, and to actually provide care that meets the standards of care.

To learn about the physicians' Code of Ethics, contact the American Medical Association at [www.ama-assn.org](http://www.ama-assn.org) (see "Important Internet Links to Other Resources and Agencies"). The main idea behind standards of care is that all physicians must provide the care which could reasonably be expected under the specific circumstances of the case. There are generally accepted protocols of acting for almost every situation which may arise in medicine.

If you are using hospice services, the attending physician is required to meet the standards of care, even if the attending physician is not a hospice specialist.<sup>(20)</sup> Providing adequate and appropriate medications to manage symptoms the patient may be experiencing is expected. The standard is that the care must actually be adequate to meet the needs of the patient and the family.

Leaving the patient in pain without intervening is one of the most serious violations of hospice care standards. Of course, it is sometimes difficult to achieve full pain control immediately, and different dosages, medications or treatments may be necessary to reach full relief. But ignoring the patient's complaints of severe pain is not what hospice is about.

In addition to your own attending physician, you also have the hospice medical director who is required to assure that your loved one receives full, appropriate and adequate relief from pain and other distressing symptoms.<sup>(21)</sup> Hospice staff normally contact the attending physician for specific orders to relieve symptoms which cannot be handled through medications listed on the standing orders. If the attending physician does not provide the needed orders, the hospice staff are required to inform their management and the hospice medical director in order to intervene on behalf of the patient ... your loved

one. If you think your loved one is not getting adequate medication or treatment for distressing or painful symptoms, do not hesitate to request to speak to the medical director directly yourself. It is your right and the hospice's obligation under the law.

You may wonder why a hospice medical director would not intervene to over-ride an attending physician's orders if they are inadequate to help the patient achieve full comfort and pain relief. Hospices are businesses as well as providers of health care services. Again, it comes down to money. The referral sources for patients are the hospitals, nursing homes and physicians. In most cases, the attending physicians in your community determine which hospice is used by the patients. The physician refers the patients to the hospice of his or her choice.

If a hospice displeases or offends a physician in the community, the physician may no longer refer patients to that hospice. The hospice's census or total number of patients would likely decrease and the hospice would receive less reimbursement for fewer patients receiving hospice care. Hospices compete against each other for the hospice patients. Although it is despicable, there are hospices which abandon the patient to his or her pain, rather than cross the physician's will and arouse his or her anger. That is why you need to be your own advocate for your loved one's welfare; be assertive and demand proper, appropriate and adequate care so that your loved one is kept comfortable throughout.

## **STANDARDS OF CARE - NURSING**

Hospices must provide adequate nursing care to meet the needs of the patient.<sup>(22)</sup> That is the law. Most hospices will try to provide adequate care to help you and your loved one through this difficult time. The RN case manager will work hard to make sure everything you need will be in place: adequate staff, equipments, supplies and medications. She will work with your attending physician to get everything ordered from the time your loved one enrolls in the hospice program.

Hopefully it will not be a problem for you, but if you are not getting the help you need from your hospice, you need to speak up and let them know you are aware of this standard. All nurses, including hospice nurses, are trained to provide care according to the accepted standards of practice within the nursing field. Standards of nursing practice

and the "Code for Nurses" can be found by contacting the American Nurses Association or your state's nursing association. Your state's nursing association can be accessed by calling telephone listing information for the capitol of your state. (See "Links to Other Important Resources" - "American Nurses Association," "State Nursing Associations" and "RN Magazine").

The nurse's license authorizes her to perform assessments of patients, create nursing plans of care, perform skilled nursing procedures, provide necessary aspects of nursing care, and many other tasks. The nurse's license requires her to make sure the patient's needs are met. The registered nurse is authorized to supervise, direct and educate other nursing staff with less training.

### Nursing Services in a Hospice Facility

If your loved one is placed in a hospice facility, an RN must be physically at the facility every shift, 24 hours in each day. If you do not know the titles or qualifications of your hospice's staff, you need to ask. It is reasonable to request that staff wear I.D. badges or tags to identify the name and professional status of each nurse. The information you receive from a licensed nurse should be much more reliable than information provided by nursing assistants or volunteers at the facility. It is sometimes difficult to know who the licensed staff are, because some hospices may allow staff to wear casual "street dress" to have a more home-like atmosphere.

Federal regulations state that for a hospice that provides care in its own inpatient facility, "The facility provides 24-hour nursing services which are sufficient to meet total nursing needs and which are in accordance with the patient plan of care. Each patient receives treatments, medications, and diet as prescribed, and is kept comfortable, clean, well-groomed, and protected from accident, injury, and infection." "Each shift must include a registered nurse who provides direct patient care." (See 42 CFR 418.100 subpart a). If your loved one is in a hospice facility, according to the law, the hospice must provide adequate staff to keep all patients clean, well-groomed, and protected from accident, injury or infection, and to provide all the care needed to meet your loved one's needs!

### Nursing Services at Home During A Crisis

Hospices are required to provide nursing services in your own home when your loved one experiences a crisis! Crisis causing symptoms can vary:

- severe pain out of control,  
respiratory distress,
- uncontrolled agitation (which can be common in the terminally ill),
- seizure activity

- uncontrolled vomiting or bleeding,
- the active phase of dying (at the very end)

Continuous around-the-clock nursing is a specific level of care within hospice which must be provided if needed. This level of care is provided when the hospice provides the nursing staff which is adequate to meet the nursing needs of your loved one, when 8 or more hours of continuous nursing are provided in a day, and when at least 50% of that nursing care is directly provided by an LPN or an RN in your home.

If a crisis is occurring, then the nursing staff must remain in the home until the crisis is resolved through nursing and medical interventions. The RN case manager will be very closely monitoring the patient's condition and contacting the attending physician as needed. If your loved one is determined to stay at home to die, and a crisis occurs, make sure the hospice provides this Continuous Nursing Care in your own home. Some hospices make it a practice to use a crisis in order to illegally manipulate patients into the hospice's own inpatient facility where they collect more money for room and board. The family is never told that Continuous Nursing Care could be provided at home, and the family is told that there is only one option: transfer your loved one to our facility where he can get the care he needs ... they do not tell you the hospice is required to provide care at home and try to control symptoms there, if the patient wishes.

The Code of Federal Regulations (42 CFR Section 418.204) specifically states that:

"nursing care may be covered on a continuous basis for as much as 24 hours a day during periods of crisis as necessary to maintain an individual at home. Either homemaker or home health aide services or both may be covered on a 24-hour continuous basis during periods of crisis but care during these periods must be predominantly [licensed] nursing care. A period of crisis is a period in which the individual requires continuous care to achieve palliation [relief from the symptoms] or management of acute medical symptoms."

Continuous Home Nursing care is a covered benefit in hospice; you and your loved one are entitled to it!

## Licensed Practical Nurses

The licensed practical nurse can perform almost all nursing procedures, but is not authorized to supervise or direct other nurses with lesser training. Even if an RN is not

physically present when LPNs provide care, the RN case manager is responsible for the care being provided to the patient by other nurses under her supervision. The LPNs and nursing assistants or aides all work under the license of the RN (even though the LPN has her own license to practice). Only RNs, LPNs, or family members (who have been trained to do so) can give medications to patients.

## Home Health Aide and Homemaker Services

Hospices must provide adequate home health aide and homemaker services to meet the needs of the patients.<sup>(23)</sup> aides may assist the patient with general Activities of Daily Living (ADLs) like bathing, feeding, dressing, and so on. Sometimes the family is unable to give the bath, or doesn't know how to deal with certain obstacles to bedside care caused by the patient's deteriorating condition, weakness or disability.

Hospice aides are not licensed to give medications to patients.<sup>(24)</sup> Generally speaking, only if an aide has attended a State-approved training program in medication administration, only then can an aide legally give medications to a patient. The family can always give medications to the patient, but in most cases, not an aide. If a hospice sends out aides to provide bedside care, that is appropriate. If medications need to be given, either the family must give the medications or the hospice must arrange for LPNs or RNs to give the medication.

If an aide is being sent out to administer medications, she *must* have special training in medication administration or there is a violation of the standards. Because home health aides are not trained in the use of medications, they do not have the knowledge to properly assess a patient, determine when a medication may need to be adjusted in dosage or if it is ineffective. RNs and LPNs are trained to recognize the need to call the physician for new orders regarding medications. Hospices may save money by sending out aides when licensed LPNs or RNs are required under the law, but for your loved one to receive the very best care, you need to make sure LPNs and RNs are providing care when there are difficult or emergency situations occurring.

## Professional Competence and the Hospice Nurse's Role

Hospice nurses are required to maintain their professional competence, follow the Code of Ethics for all nurses and provide care which meets the standards of care. All nurses are required to enroll in programs of continuing education, and all home health aides must attend regular inservices at the hospice for training. Hospice nurses, like all nurses, are intermediaries in communicating the patient's status and needs to the attending physician. Because of the nature of hospice, the nurse's role is expanded and becomes even more important to your loved one. The nurse may, in specific situations, start giving medications approved by the physician in the standing orders.

In addition, the hospice nurse becomes the "eyes and ears" of the physician, telling the physician what is occurring, what the vital signs are, what symptoms have arisen and generally providing all information necessary for the physician to make appropriate medical orders for the patient ... based on the information given by the nurse. All nursing personnel must regularly report to the RN case manager, and the RN case manager must regularly report to the attending physician ... especially if the patient's pain or other symptoms are not relieved. It is important for you to clearly notify the RN case manager about any needs or problems your loved one may be experiencing.

## **YOU CONTROL THE CARE YOU GET**

Whether your loved one receives quality hospice care which meets his or her needs is up to you. You cannot assume that just because you have signed up with a hospice that "everything will be taken care of." Certainly, most patients and families expect that "everything will be taken care of," and the law requires that "everything will be taken care of." The reality today, however, is that many hospices are just like other health care provider/agencies ... a business which happens to be in the business of providing health care. When hospice is approached as a business, without respect for the standards of care, so many patients and families suffer needlessly and tragically. By being informed about the standards of care in hospice and what services should be provided, you can help protect your loved one and yourselves from exploitation. That is a major goal of our mission at Hospice Patients Alliance.

In all aspects of health care today, you need to be informed as much as possible and assertive, in order to get the very best care you are entitled to. Making sure the hospice staff is "on the ball" and making sure your loved one is comfortable, is your job. Hopefully, you will not need to intervene on behalf of your loved one, because the hospice is fulfilling its mission to provide quality hospice care. Remember that the RN case manager is the first contact for problem resolution. You can always contact the

hospice's medical director or your own attending physician if problems are not being resolved in a timely manner.

Waiting weeks for action is simply not acceptable. If your loved one is in pain or suffering, the hospice needs to act promptly; the attending physician needs to act, and if not, the hospice's medical director must act. Please make sure that they are contacted and that necessary changes in care are made, for your loved one's sake. As with all health care, "the squeaky wheel gets the grease." By speaking up, there is a much better chance your loved one will get the care needed.

## **YOUR RIGHTS AS A HOSPICE PATIENT**

### **Informed Consent**

Knowing your rights as a hospice patient is essential if any difficulties arise in the care being provided to you. Being fully informed before any health care is provided is called "informed consent." You cannot reasonably make any decision about the type of care you desire if you do not know what is available and what all your options are. For this reason, informed consent is mandatory in all health care settings, including hospice. [\(25\)](#)

Making sure all patients receive informed consent is so important that the federal government makes "informed consent" a "Condition of Participation" in the Medicare program. All hospices must have you sign an informed consent form before admitting you to the program. Hospices that do not provide informed consent could be excluded from receiving any reimbursements through Medicare. Medicaid and private insurance companies also require that complete informed consent be provided to the patient.

### **Types of Services and Levels of Care**

The idea behind an informed consent form is that you learn about all the services which may be available to you. Briefly, the types of services you are entitled to are: visits from

RNs, LPNs, home health aides, home service aides, medical social workers, chaplains, counselors, dietitians, therapists; hospice medical director's oversight of your care, and all the medicines, equipment, treatments, and supplies needed to manage the symptoms of your terminal illness, any related conditions or problems, and help you to be comfortable. The four Levels of Care you are entitled to are:

- 85. General Home Care,
- 86. Respite Care,
- 87. Continuous Nursing Care in your own home or
- 88. Inpatient Care in a hospice facility.

You need to be aware when enrolling in a hospice program that you can always change your mind and withdraw from the hospice program at any time. For example, if you were to suddenly become aware of a new treatment which your physician might use to actually treat and cure the terminal illness, you could return to the "curative" mode of medical care and be treated, just as you were before entering the hospice program. For Medicare recipients, it means that you let go of the hospice benefit and resume regular Medicare coverage.

### Your Plan of Care Must Be Adequate to Meet Your Needs

The types of services and levels of care you receive depends upon your condition and changing needs. The most important requirement is that the hospice must meet your needs for care related to the terminal illness.<sup>(26)</sup> And the laws governing hospice mandate that you, the patient, make the decision about what type of care you will accept. You have the right to choose to stay at your own home till the very end or to enter a facility. The hospice Interdisciplinary Team will assess your needs from all angles and come up with a Plan of Care which your attending physician approves. You have the right to refuse care you do not want or to accept the care you do want.

### Making the Decision to Express Your Wishes

While most of us have thought about the type of care we would not want under certain circumstances, it is highly likely that we have not expressed our wishes to our entire family. We may have told our wives or husbands, but have we told our parents or children, for example? Have we told our brothers or sisters? The answers to these

questions depend upon the exact type of relationships we have built within our family unit. Speaking about our own death is perhaps one of the most difficult things we could do. We may be afraid of upsetting our family by discussing it. The family may be afraid of discussing it in front of you. But if you do not take charge and discuss it now, it may never be discussed! The implications can be disastrous for you and your family.

You may assume that someone in your family may be fully aware of your personal attitude in regard to specific forms of health care interventions and treatments. However, others may be entirely unaware or uncaring about your wishes. You may or may not be surprised to learn that it is possible for family members to argue vehemently about the type of care you will be given. Love, anger, guilt and religious beliefs all come into play influencing each member to speak their mind, in agreement or disagreement.

One of the most terrible forms of suffering your loved ones may experience could be watching you endure a treatment or intervention that they know you never wanted and would object to strongly, were you able to voice your opinion. You never know when your body will weaken to the point where you will not be able to speak or communicate your wishes. For your sake and your family's welfare, decide to speak openly about your wishes and put it down on paper formally. The hospice social worker is fully qualified to assist you in making these arrangements.

## Advanced Directives and DNR Forms

It is important to make a legally binding written statement about what your wishes are: about the type of care you do or do not want, what types of interventions you would accept in different situations, what types of efforts should or should not be made to save you in the event your heart or lungs stopped functioning. You can accomplish this by filling out:

- a Medical Durable Power of Attorney Form (which clarifies in advance what your directives or wishes are ... an "Advanced Directive"
- and a DNR form (which should specify whether or not you wish to be resuscitated in the event your heart or breathing stop.

Without a DNR form, you will likely end up being resuscitated with CPR and acute hospital care! Without a DNR form, you may suffer even more while medical personnel try to get your heart and lungs going again!

When a Medical Durable Power of Attorney form is filled out, your authorized Representative will be authorized to make decisions for you only when, and if, you yourself cannot make the decision due to mental or physical incapacity. Being "authorized" means that the physicians and hospice staff are legally bound to follow the decisions of the representative you choose. It also protects you from having decisions made by others who do not know your wishes or do not care about your wishes and who might try to impose their "philosophy" and "beliefs" on you against your will.

The Medical Durable Power of Attorney only becomes effective when and if you are in a coma and cannot be awakened, or if you are no longer mentally able to understand and make decisions about your care. If you have any questions about these forms, which are all legal documents, you should speak with the hospice medical social worker, your physician and an attorney. (See the section on "Do Not Resuscitate Orders, Power of Attorney Forms, Advanced Directives and Patient Comfort).

## **YOUR RIGHTS AS A FAMILY MEMBER OR CARE GIVER**

One of the major differences between hospice and other health care is the designation of the family unit as an integral part of the process. While the hospice's plan of care for your loved one's terminal illness is obviously the main focus of the hospice's efforts, the plan of care must address the family/care giver's needs as well.<sup>(27)</sup> The mission of hospice care is to help the family get through this difficult time while providing all the care needed by your loved one.

At the time of admission to hospice, the RN case manager or admission staff will assess the family's needs for various types of services. As time goes on the RN case manager may become aware of new needs which have arisen, and arrange for further assistance to the family. If the terminal illness is causing financial challenges, the hospice social worker can make arrangements to find assistance from many sources. Emotional difficulties can be addressed through informal or formal counseling, either in private individually or with the family as a group. If legal advice is needed, the hospice may help

you locate a knowledgeable attorney. Bereavement counseling must be made available to you for up to one year after the death of your loved one.[\(28\)](#)

While some may state that they "do not need any help," the loss of our close family members can be so traumatic that some survivors suffer from a full clinical depression. The emotional pain may be too deep to admit to ourselves or others. Even if it doesn't come to depression, counseling can be extremely helpful. Sometimes we do not really feel the full effects of our loss until months later ... we can shield ourselves from the pain in many ways as a "defense mechanism." But time has a way of bringing the truth of the matter to the fore. The death of a loved one is something we may get used to, but we may not fully "get over it" completely. The loss is real and will always be. Bereavement counseling can make a great difference in helping you in such difficult times.

## RECOMMENDED READING & PUBLICATIONS

Agency for Health Care Policy and Research (AHCPR): (tel. 800-358-9295)

Clinical Practice Guideline Number 9: Management of Cancer Pain

Quick Reference Guide for Clinicians (management of cancer pain);

Patient Guide to Managing Cancer Pain

All available free, and excellent for anyone who is concerned about proper pain control.

Explains the standards in the medical field for treating terminal cancer pain

Christian Medical and Dental Society (CMDA), No Mercy

An important video revealing the dark side of physician-assisted suicide and euthanasia, which is not "merciful" at all. This important video documentary may be purchased by calling 888-231-2637 (Life & Health Resources) or CMDA tel: 423-844-1000/fax: 423-844-1017, 501 Fifth St., POB 7500, Bristol, TN 37621

D.Doyle, GWC Hanks, N McDonald, Editors:

The Oxford Textbook of Palliative Medicine

New York 1993, Oxford University Press

CR Gallaher-Allred, MO Amenta, editors:

Nutrition and Hydration in Hospice Care:

Needs, Strategies, Ethics

New York, 1993, The Haworth Press

Carlos Gomez, MD,

Regulating Death - Euthanasia and the Case of the Netherlands

New York, 1991, The Free Press

Dr. Gomez presents shocking evidence that euthanasia in the Netherlands is truly out of control and that safeguards for the so-called proper implementation of medical killing are routinely violated, and that the courts and physician review have not stopped or even condemned involuntary euthanasia cases. On the contrary, physicians in the Netherlands are encouraged to provide euthanasia (which cuts costs for the Dutch socialized medicine budget) and review of violations of the safeguards are entrusted to physicians who favor the option of euthanasia. Dr. Gomez explains that patient "willingness" to be euthanized is not always voluntary, but rather may be a result of pressures from the physician or a family feeling burdened by the patient's need for ongoing care.

Herbert Hendin, M.D.

Seduced by Death - Doctors, Patients, and the Dutch Cure

W.W. Norton & Company, New York City, NY 1997

Dr. Hendin is Professor of Psychiatry at New York Medical College and Exec. Dir. of the American Foundation for Suicide Prevention, toll-free: 888-333-AFSP, PHONE: 212-363-3500, <http://www.afsp.org> Presents the results of exhaustive research and interviews about euthanasia in the Netherlands; its impact on patient rights. He clearly shows how patients are often pressured into euthanasia and how euthanasia may be performed on patients who have not given permission, were not informed of the intention to euthanize them, or who were depressed and may have decided against euthanasia if they had been offered psychiatric counseling. Euthanasia represents one of the greatest threats to real hospice care in the world. Where euthanasia flourishes, education in pain management and hospice declines.

DP Irish, KF Lundquist, VJ Nelson:

Ethnic Variations in Dying, Death and Grief

Bristol, PA 1993 Hemisphere Press

Elizabeth Kubler-Ross, M.D.: On Death and Dying

The classic reference on death and the dying process. Well-accepted and well-researched conclusions. One of the most important pivotal works with world-wide impact. Written by one of the key researchers of hospice.

Elizabeth Kubler-Ross, MD: Death: The Final Stage of Growth

Englewood Cliffs, NJ 1975

Rev. Samuel Oliver, MDiv, BCC:

What the Dying Teach Us: Lessons On Living

The Haworth Pastoral Press, Binghamton, NY 1998

An experienced hospice minister reveals the heart of the Hospice mission and conveys the inner experience of hospice care, death and dying, and questions about the meaning of life, death, and the Spirit. Get back in touch with what is really going on during the most intimate moments of the dying process as well as life itself.

DC Sheehan, WB Forman: Hospice & Palliative Care: Concepts & Practice

Boston, 1996, Jones & Bartlett

An excellent reference for the professional hospice care provider. Concise, reliable information presented in a very readable format.



# TEXT OF FEDERAL LAW ON HOSPICE

[The law presented below is as posted at the Government Printing Office Website at:  
[www.access.gpo.gov/nara/cfr/waisidx\\_00/42cfr418\\_00.html](http://www.access.gpo.gov/nara/cfr/waisidx_00/42cfr418_00.html)  
[Revised as of October 1, 2000]

[Code of Federal Regulations]  
[Title 42, Volume 2, Parts 400 to 429]  
[Revised as of October 1, 2000]  
From the U.S. Government Printing Office via GPO Access  
[CITE: 42CFR418.1]

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## TITLE 42--PUBLIC HEALTH CHAPTER IV--HEALTH CARE FINANCING ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

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## Subpart A--General Provision and Definitions

Sec. 418.1 Statutory basis.

This part implements section 1861(dd) of the Social Security Act. Section 1861(dd) specifies services covered as hospice care and the conditions that a hospice program must meet in order to participate in the Medicare program. The following sections of the Act are also pertinent:

- (a) Sections 1812(a) (4) and (d) of the Act specify eligibility requirements for the individual and the benefit periods.
- (b) Section 1813(a)(4) of the Act specifies coinsurance amounts.
- (c) Sections 1814(a)(7) and 1814(i) of the Act contain conditions and limitations on coverage of, and payment for, hospice care.
- (d) Sections 1862(a) (1), (6) and (9) of the Act establish limits on hospice coverage.

[48 FR 56026, Dec. 16, 1983, as amended at 57 FR 36017, Aug. 12, 1992]

[CITE: 42CFR418.2]

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## Subpart A--General Provision and Definitions

### Sec. 418.2 Scope of part.

Subpart A of this part sets forth the statutory basis and scope and defines terms used in this part. Subpart B specifies the eligibility requirements and the benefit periods. Subpart C specifies conditions of participation for hospices. Subpart D describes the covered services and specifies the limits on services covered as hospice care. Subpart E specifies the reimbursement methods and procedures. Subpart F specifies coinsurance amounts applicable to hospice care.

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### Sec. 418.3 Definitions.

For purposes of this part--

Attending physician means a physician who--

(a) Is a doctor of medicine or osteopathy; and

(b) Is identified by the individual, at the time he or she elects to receive hospice care, as having the most significant role in the determination and delivery of the individual's medical care.

Bereavement counseling means counseling services provided to the individual's family after the individual's death.

Cap period means the twelve-month period ending October 31 used in the application of the cap on overall hospice reimbursement specified in Sec. 418.309.

Employee means an employee (defined by section 210(j) of the Act) of the hospice or, if the hospice is a subdivision of an agency or organization, an employee of the agency or organization who is appropriately trained and assigned to the hospice unit. ``Employee" also refers to a volunteer under the jurisdiction of the hospice.

Hospice means a public agency or private organization or subdivision of either of these that--is primarily engaged in providing care to terminally ill individuals.

Physician means physician as defined in Sec. 410.20 of this chapter.

Representative means an individual who has been authorized under State law to terminate medical care or to elect or revoke the election of hospice care on behalf of a terminally ill individual who is mentally or physically incapacitated.

Social worker means a person who has at least a bachelor's degree from a school accredited or approved by the Council on Social Work Education.

Terminally ill means that the individual has a medical prognosis that his or her life expectancy is 6 months or less if the illness runs its normal course.

[48 FR 56026, Dec. 16, 1983, as amended at 52 FR 4499, Feb. 12, 1987; 50 FR 50834, Dec. 11, 1990]

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## Subpart B--Eligibility, Election and Duration of Benefits

### Sec. 418.20 Eligibility requirements.

In order to be eligible to elect hospice care under Medicare, an individual must be--

(a) Entitled to Part A of Medicare; and

(b) Certified as being terminally ill in accordance with

Sec. 418.22.

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Sec. 418.21 Duration of hospice care coverage--Election periods.

(a) Subject to the conditions set forth in this part, an individual may elect to receive hospice care during one

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or more of the following election periods:

- (1) An initial 90-day period.
  - (2) A subsequent 90-day period.
  - (3) A subsequent 30-day period.
  - (4) A subsequent extension period of unlimited duration during the individual's lifetime.
- (b) The periods of care are available in the order listed and may be elected separately at different times.

[55 FR 50834, Dec. 11, 1990, as amended at 57 FR 36017, Aug. 12, 1992]  
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Sec. 418.22 Certification of terminal illness.

(a) Timing of certification--(1) General rule. The hospice must obtain written certification of terminal illness for each of the periods listed in Sec. 418.21, even if a single election continues in effect for two, three, or four periods, as provided in Sec. 418.24(c).

(2) Basic requirement. Except as provided in paragraph (a)(3) of this section, the hospice must obtain the written certification no later than two calendar days after the period begins.

(3) Exception. For the initial 90-day period, if the hospice cannot obtain the written certifications within two calendar days, it must obtain oral certifications within two calendar days, and written certifications no later than eight calendar days after the period begins.

(b) Content of certification. The certification must specify that the individual's prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course.

(c) Sources of certification. (1) For the initial 90-day period, the hospice must obtain written certification statements (and oral certification statements if required under paragraph (a)(3) of this section) from--

- (i) The medical director of the hospice or the physician member of the hospice interdisciplinary group; and
  - (ii) The individual's attending physician if the individual has an attending physician.
- (2) For subsequent periods, the only requirement is certification by one of the physicians listed in paragraph (c)(1)(i) of this section.
- (d) Maintenance of records. Hospice staff must--
- (1) Make an appropriate entry in the patient's medical record as soon as they receive an oral certification; and
  - (2) File written certifications in the medical record.

[55 FR 50834, Dec. 11, 1990, as amended at 57 FR 36017, Aug. 12, 1992]  
[Page 694-695]

#### Sec. 418.24 Election of hospice care.

- (a) Filing an election statement. An individual who meets the eligibility requirement of Sec. 418.20 may file an election statement with a particular hospice. If the individual is physically or mentally incapacitated, his or her representative (as defined in Sec. 418.3) may file the election statement.
- (b) Content of election statement. The election statement must include the following:
  - (1) Identification of the particular hospice that will provide care to the individual.
  - (2) The individual's or representative's acknowledgement that he or she has been given a full understanding of the palliative rather than curative nature of hospice care, as it relates to the individual's terminal illness.
  - (3) Acknowledgement that certain Medicare services, as set forth in paragraph (d) of this section, are waived by the election.
  - (4) The effective date of the election, which may be the first day of hospice care or a later date, but may be no earlier than the date of the election statement.
  - (5) The signature of the individual or representative.
- (c) Duration of election. An election to receive hospice care will be considered to continue through the initial election period and through the subsequent election periods without a break in care as long as the individual--
  - (1) Remains in the care of a hospice; and
  - (2) Does not revoke the election under the provisions of Sec. 418.28.
- (d) Waiver of other benefits. For the duration of an election of hospice care, an individual waives all rights to Medicare payments for the following services:
  - (1) Hospice care provided by a hospice other than the hospice designated by the individual (unless provided under

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arrangements made by the designated hospice).

(2) Any Medicare services that are related to the treatment of the terminal condition for which hospice care was elected or a related condition or that are equivalent to hospice care except for services--

(i) Provided by the designated hospice:

(ii) Provided by another hospice under arrangements made by the designated hospice; and

(iii) Provided by the individual's attending physician if that physician is not an employee of the designated hospice or receiving compensation from the hospice for those services.

(e) Re-election of hospice benefits. If an election has been revoked in accordance with Sec. 418.28, the individual (or his or her representative if the individual is mentally or physically incapacitated) may at any time file an election, in accordance with this section, for any other election period that is still available to the individual.

[55 FR 50834, Dec. 11, 1990]

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Sec. 418.28 Revoking the election of hospice care.

(a) An individual or representative may revoke the individual's election of hospice care at any time during an election period.

(b) To revoke the election of hospice care, the individual or representative must file a statement with the hospice that includes the following information:

(1) A signed statement that the individual or representative revokes the individual's election for Medicare coverage of hospice care for the remainder of that election period.

(2) The date that the revocation is to be effective. (An individual or representative may not designate an effective date earlier than the date that the revocation is made).

(c) An individual, upon revocation of the election of Medicare coverage of hospice care for a particular election period--

(1) Is no longer covered under Medicare for hospice care;

(2) Resumes Medicare coverage of the benefits waived under Sec. 418.24(e)(2); and

(3) May at any time elect to receive hospice coverage for any other hospice election periods that he or she is eligible to receive.

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Sec. 418.30 Change of the designated hospice.

- (a) An individual or representative may change, once in each election period, the designation of the particular hospice from which hospice care will be received.
- (b) The change of the designated hospice is not a revocation of the election for the period in which it is made.
- (c) To change the designation of hospice programs, the individual or representative must file, with the hospice from which care has been received and with the newly designated hospice, a statement that includes the following information:
  - (1) The name of the hospice from which the individual has received care and the name of the hospice from which he or she plans to receive care.
  - (2) The date the change is to be effective.

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Subpart C--Conditions of Participation--General Provisions and Administration

Sec. 418.50 Condition of participation--General provisions.

- (a) Standard: Compliance. A hospice must maintain compliance with the conditions of this subpart and subparts D and E of this part.
- (b) Standard: Required services. A hospice must be primarily engaged in providing the care and services described in Sec. 418.202, must provide bereavement counseling and must--
  - (1) Make nursing services, physician services, and drugs and biologicals routinely available on a 24-hour basis;
  - (2) Make all other covered services available on a 24-hour basis to the extent necessary to meet the needs of individuals for care that is reasonable and necessary for the palliation and management of terminal illness and related conditions; and
  - (3) Provide these services in a manner consistent with accepted standards of practice.
- (c) Standard: Disclosure of information. The hospice must meet the disclosure of information requirements at Sec. 420.206 of this chapter.

[48 FR 56026, Dec. 16, 1983, as amended at 55 FR 50834, Dec. 11, 1990]

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Sec. 418.52 Condition of participation--Governing body.

A hospice must have a governing body that assumes full legal responsibility for determining, implementing and monitoring policies governing the hospice's total operation. The governing body must designate an individual who is responsible for the day to day management of the hospice program. The governing body must also ensure that all services provided are consistent with accepted standards of practice.

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Sec. 418.54 Condition of participation--Medical director.

The medical director must be a hospice employee who is a doctor of medicine or osteopathy who assumes overall responsibility for the medical component of the hospice's patient care program.

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Sec. 418.56 Condition of participation--Professional management.

Subject to the conditions of participation pertaining to services in Secs. 418.80 and 418.90, a hospice may arrange for another individual or entity to furnish services to the hospice's patients. If services are provided under arrangement, the hospice must meet the following standards:

- (a) Standard: Continuity of care. The hospice program assures the continuity of patient/family care in home, outpatient, and inpatient settings.
- (b) Standard: Written agreement. The hospice has a legally binding written agreement for the provision of arranged services. The agreement includes at least the following:
  - (1) Identification of the services to be provided.
  - (2) A stipulation that services may be provided only with the express authorization of the hospice.
  - (3) The manner in which the contracted services are coordinated, supervised, and evaluated by the hospice.
  - (4) The delineation of the role(s) of the hospice and the contractor in the admission process, patient/family assessment, and the interdisciplinary group care conferences.
  - (5) Requirements for documenting that services are furnished in accordance with the agreement.
  - (6) The qualifications of the personnel providing the services.
- (c) Standard: Professional management responsibility. The hospice retains professional management responsibility for those services and ensures that they are furnished in a safe

and effective manner by persons meeting the qualifications of this part, and in accordance with the patient's plan of care and the other requirements of this part.

(d) Standard: Financial responsibility. The hospice retains responsibility for payment for services.

(e) Standard: Inpatient care. The hospice ensures that inpatient care is furnished only in a facility which meets the requirements in Sec. 418.98 and its arrangement for inpatient care is described in a legally binding written agreement that meets the requirements of paragraph (b) and that also specifies, at a minimum--

(1) That the hospice furnishes to the inpatient provider a copy of the patient's plan of care and specifies the inpatient services to be furnished;

(2) That the inpatient provider has established policies consistent with those of the hospice and agrees to abide by the patient care protocols established by the hospice for its patients;

(3) That the medical record includes a record of all inpatient services and events and that a copy of the discharge summary and, if requested, a copy of the medical record are provided to the hospice;

(4) The party responsible for the implementation of the provisions of the agreement; and

(5) That the hospice retains responsibility for appropriate hospice care training of the personnel who provide the care under the agreement.

[48 FR 56026, Dec. 16, 1983; 48 FR 57282, Dec. 29, 1983]

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#### Sec. 418.58 Condition of participation--Plan of care.

A written plan of care must be established and maintained for each individual admitted to a hospice program,

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and the care provided to an individual must be in accordance with the plan.

(a) Standard: Establishment of plan. The plan must be established by the attending physician, the medical director or physician designee and interdisciplinary group prior to providing care.

(b) Standard: Review of plan. The plan must be reviewed and updated, at intervals specified in the plan, by the attending physician, the medical director or physician designee and interdisciplinary group. These reviews must be documented.

(c) Standard: Content of plan. The plan must include an assessment of the individual's

needs and identification of the services including the management of discomfort and symptom relief. It must state in detail the scope and frequency of services needed to meet the patient's and family's needs.

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Sec. 418.60 Condition of participation--Continuation of care.

A hospice may not discontinue or diminish care provided to a Medicare beneficiary because of the beneficiary's inability to pay for that care.

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Sec. 418.62 Condition of participation--Informed consent.

A hospice must demonstrate respect for an individual's rights by ensuring that an informed consent form that specifies the type of care and services that may be provided as hospice care during the course of the illness has been obtained for every individual, either from the individual or representative as defined in Sec. 418.3.

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Sec. 418.64 Condition of participation--Inservice training.

A hospice must provide an ongoing program for the training of its employees.

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Sec. 418.66 Condition of participation--Quality assurance.

A hospice must conduct an ongoing, comprehensive, integrated, self- assessment of the quality and appropriateness of care provided, including inpatient care, home care and care provided under arrangements. The findings are used by the hospice to correct identified problems and to revise hospice policies if necessary. Those responsible for the quality assurance program must--

- (a) Implement and report on activities and mechanisms for monitoring the quality of patient care;
- (b) Identify and resolve problems; and
- (c) Make suggestions for improving patient care.

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Sec. 418.68 Condition of participation--Interdisciplinary group.

The hospice must designate an interdisciplinary group or groups composed of individuals who provide or supervise the care and services offered by the hospice.

(a) Standard: Composition of group. The hospice must have an interdisciplinary group or groups that include at least the following individuals who are employees of the hospice:

(1) A doctor of medicine or osteopathy.

(2) A registered nurse.

(3) A social worker.

(4) A pastoral or other counselor.

(b) Standard: Role of group. The interdisciplinary group is responsible for--

(1) Participation in the establishment of the plan of care;

(2) Provision or supervision of hospice care and services;

(3) Periodic review and updating of the plan of care for each individual receiving hospice care; and

(4) Establishment of policies governing the day-to-day provision of hospice care and services.

(c) If a hospice has more than one interdisciplinary group, it must designate in advance the group it chooses to execute the functions described in paragraph (b)(4) of this section.

(d) Standard: Coordinator. The hospice must designate a registered nurse to coordinate the implementation of the plan of care for each patient.

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Sec. 418.70 Condition of participation--Volunteers.

The hospice in accordance with the numerical standards, specified in paragraph (e) of this section, uses volunteers, in defined roles, under the supervision of a designated hospice employee.

(a) Standard: Training. The hospice must provide appropriate orientation

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and training that is consistent with acceptable standards of hospice practice.

(b) Standard: Role. Volunteers must be used in administrative or direct patient care roles.

(c) Standard: Recruiting and retaining. The hospice must document active and ongoing efforts to recruit and retain volunteers.

(d) Standard: Cost saving. The hospice must document the cost savings achieved through the use of volunteers. Documentation must include--

(1) The identification of necessary positions which are occupied by volunteers;

(2) The work time spent by volunteers occupying those positions; and

(3) Estimates of the dollar costs which the hospice would have incurred if paid employees occupied the positions identified in paragraph (d)(1) for the amount of time specified in paragraph (d)(2).

(e) Standard: Level of activity. A hospice must document and maintain a volunteer staff sufficient to provide administrative or direct patient care in an amount that, at a minimum, equals 5 percent of the total patient care hours of all paid hospice employees and contract staff. The hospice must document a continuing level of volunteer activity. Expansion of care and services achieved through the use of volunteers, including the type of services and the time worked, must be recorded.

(f) Standard: Availability of clergy. The hospice must make reasonable efforts to arrange for visits of clergy and other members of religious organizations in the community to patients who request such visits and must advise patients of this opportunity.

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#### Sec. 418.72 Condition of participation--Licensure.

The hospice and all hospice employees must be licensed in accordance with applicable Federal, State and local laws and regulations.

(a) Standard: Licensure of program. If State or local law provides for licensing of hospices, the hospice must be licensed.

(b) Standard: Licensure of employees. Employees who provide services must be licensed, certified or registered in accordance with applicable Federal or State laws.

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#### Sec. 418.74 Condition of participation--Central clinical records.

In accordance with accepted principles of practice, the hospice must establish and maintain a clinical record for every individual receiving care and services. The record must be complete, promptly and accurately documented, readily accessible and systematically organized to facilitate retrieval.

(a) Standard: Content. Each clinical record is a comprehensive compilation of information. Entries are made for all services provided. Entries are made and signed by the person providing the services. The record includes all services whether furnished directly or under arrangements made by the hospice. Each individual's record contains--

(1) The initial and subsequent assessments;

- (2) The plan of care;
  - (3) Identification data;
  - (4) Consent and authorization and election forms;
  - (5) Pertinent medical history; and
  - (6) Complete documentation of all services and events (including evaluations, treatments, progress notes, etc.).
- (b) Standard; Protection of information. The hospice must safeguard the clinical record against loss, destruction and unauthorized use.

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#### Sec. 418.80 Condition of participation--Furnishing of core services.

Except as permitted in Sec. 418.83, a hospice must ensure that substantially all the core services described in this subpart are routinely provided directly by hospice employees. A hospice may use contracted staff if necessary to supplement hospice employees in order to meet the needs of patients during periods of peak patient loads or under extraordinary circumstances. If contracting is used, the hospice must maintain professional, financial, and administrative responsibility for the services and must assure that the qualifications of staff and services provided meet the requirements specified in this subpart.

[52 FR 7416, Mar. 11, 1987, as amended at 55 FR 50835, Dec. 11, 1990]  
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#### Subpart D--Conditions of Participation: Core Services

#### Sec. 418.82 Condition of participation--Nursing services.

The hospice must provide nursing care and services by or under the supervision of a registered nurse.

- (a) Nursing services must be directed and staffed to assure that the nursing needs of patients are met.
- (b) Patient care responsibilities of nursing personnel must be specified.
- (c) Services must be provided in accordance with recognized standards of practice.

Sec. 418.83 Nursing services--Waiver of requirement that substantially all nursing services be routinely provided directly by a hospice.

(a) HCFA may approve a waiver of the requirement in Sec. 418.80 for nursing services provided by a hospice which is located in a non-urbanized area. The location of a hospice that operates in several areas is considered to be the location of its central office. The hospice must provide evidence that it was operational on or before January 1, 1983, and that it made a good faith effort to hire a sufficient number of nurses to provide services directly. HCFA bases its decision as to whether to approve a waiver application on the following:

- (1) The current Bureau of the Census designations for determining non-urbanized areas.
  - (2) Evidence that a hospice was operational on or before January 1, 1983 including:
    - (i) Proof that the organization was established to provide hospice services on or before January 1, 1983;
    - (ii) Evidence that hospice-type services were furnished to patients on or before January 1, 1983; and
    - (iii) Evidence that the hospice care was a discrete activity rather than an aspect of another type of provider's patient care program on or before January 1, 1983.
  - (3) Evidence that a hospice made a good faith effort to hire nurses, including:
    - (i) Copies of advertisements in local newspapers that demonstrate recruitment efforts;
    - (ii) Job descriptions for nurse employees;
    - (iii) Evidence that salary and benefits are competitive for the area; and
    - (iv) Evidence of any other recruiting activities (e.g., recruiting efforts at health fairs and contacts with nurses at other providers in the area);
- (b) Any waiver request is deemed to be granted unless it is denied within 60 days after it is received.
- (c) Waivers will remain effective for one year at a time.
- (d) HCFA may approve a maximum of two one-year extensions for each initial waiver. If a hospice wishes to receive a one-year extension, the hospice must submit a certification to HCFA, prior to the expiration of the waiver period, that the employment market for nurses has not changed significantly since the time the initial waiver was granted.

[52 FR 7416, Mar. 11, 1987]

Sec. 418.84 Condition of participation--Medical social services.

Medical social services must be provided by a qualified social worker, under the direction of a physician.

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Sec. 418.86 Condition of participation--Physician services.

In addition to palliation and management of terminal illness and related conditions, physician employees of the hospice, including the physician member(s) of the interdisciplinary group, must also meet the general medical needs of the patients to the extent that these needs are not met by the attending physician.

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Sec. 418.88 Condition of participation--Counseling services.

Counseling services must be available to both the individual and the family. Counseling includes bereavement counseling, provided after the patient's death as well as dietary, spiritual and any other counseling services for the individual and family provided while the individual is enrolled in the hospice.

(a) Standard: Bereavement counseling. There must be an organized program for the provision of bereavement services under the supervision of a qualified professional. The plan of care for these services should reflect family needs, as well as a clear delineation of services to be provided and the frequency of service delivery (up to one year following the death of the patient). A special coverage provision for bereavement counseling is specified Sec. 418.204(c).

(b) Standard: Dietary counseling. Dietary counseling, when required, must be provided by a qualified individual.

(c) Standard: Spiritual counseling. Spiritual counseling must include notice to patients as to the availability of clergy as provided in Sec. 418.70(f).

(d) Standard: Additional counseling. Counseling may be provided by other members of the interdisciplinary group as well as by other qualified professionals as determined by the hospice.

[CITE: 42CFR418.90]

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Subpart E--Conditions of Participation: Other Services

Sec. 418.90 Condition of participation--Furnishing of other services.

A hospice must ensure that the services described in this subpart are provided directly by hospice employees or under arrangements made by the hospice as specified in Sec. 418.56.

[48 FR 56026, Dec. 16, 1983, as amended at 55 FR 50835, Dec. 11, 1990]  
[Page 700]

Sec. 418.92 Condition of participation--Physical therapy, occupational therapy, and speech-language pathology.

(a) Physical therapy services, occupational therapy services, and speech-language pathology services must be available, and when provided, offered in a manner consistent with accepted standards of practice.

(b)(1) If the hospice engages in laboratory testing outside of the context of assisting an individual in self-administering a test with an appliance that has been cleared for that purpose by the FDA, such testing must be in compliance with all applicable requirements of part 493 of this chapter.

(2) If the hospice chooses to refer specimens for laboratory testing to another laboratory, the referral laboratory must be certified in the appropriate specialties and subspecialties of services in accordance with the applicable requirements of part 493 of this chapter.

[57 FR 7135, Feb. 28, 1992]

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Sec. 418.94 Condition of participation-- Home health aide and homemaker services.

Home health aide and homemaker services must be available and adequate in frequency to meet the needs of the patients. A home health aide is a person who meets the training, attitude and skill requirements specified in Sec. 484.36 of this chapter.

(a) Standard: Supervision. A registered nurse must visit the home site at least every two weeks when aide services are being provided, and the visit must include an assessment of the aide services.

(b) Standard: Duties. Written instructions for patient care are prepared by a registered nurse. Duties include, but may not be limited to, the duties specified in Sec. 484.36(c) of this chapter.

[48 FR 56026, Dec. 16, 1983, as amended at 55 FR 50835, Dec. 11, 1990]  
[Page 700-701]

#### Sec. 418.96 Condition of participation--Medical supplies.

Medical supplies and appliances including drugs and biologicals, must be provided as needed for the palliation and management of the terminal illness and related conditions.

- (a) Standard: Administration. All drugs and biologicals must be administered in accordance with accepted standards of practice.
- (b) Standard: Controlled drugs in the patient's home. The hospice must have a policy for the disposal of controlled drugs maintained in the patient's home when those drugs are no longer needed by the patient.
- (c) Standard: Administration of drugs and biologicals. Drugs and biologicals are administered only by the following individuals:
- (1) A licensed nurse or physician.
  - (2) An employee who has completed a State-approved training program in medication administration.
  - (3) The patient if his or her attending physician has approved.
  - (4) Any other individual in accordance with applicable State and local

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laws. The persons, and each drug and biological they are authorized to administer, must be specified in the patient's plan of care.

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#### Sec. 418.98 Condition of participation--Short term inpatient care.

Inpatient care must be available for pain control, symptom management and respite purposes, and must be provided in a participating Medicare or Medicaid facility.

(a) Standard: Inpatient care for symptom control. Inpatient care for pain control and symptom management must be provided in one of the following:

- (1) A hospice that meets the condition of participation for providing inpatient care directly as specified in Sec. 418.100.

- (2) A hospital or an SNF that also meets the standards specified in Sec. 418.100 (a) and (e) regarding 24-hour nursing service and patient areas.
- (b) Standard: Inpatient care for respite purposes. Inpatient care for respite purposes must be provided by one of the following:
  - (1) A provider specified in paragraph (a) of this section.
  - (2) An ICF that also meets the standards specified in Sec. 418.100 (a) and (e) regarding 24-hour nursing service and patient areas.
- (c) Standard: Inpatient care limitation. The total number of inpatient days used by Medicare beneficiaries who elected hospice coverage in any 12-month period preceding a certification survey in a particular hospice may not exceed 20 percent of the total number of hospice days for this group of beneficiaries.
- (d) Standard: Exemption from limitation. Until October 1, 1986, any hospice that began operation before January 1, 1975 is not subject to the limitation specified in paragraph (c).

[48 FR 56026, Dec. 16, 1983, as amended at 55 FR 50835, Dec. 11, 1990]  
[Page 701-703]

#### Sec. 418.100 Condition of participation Hospices that provide inpatient care directly.

A hospice that provides inpatient care directly must comply with all of the following standards.

- (a) Standard: Twenty-four-hour nursing services. (1) The facility provides 24-hour nursing services which are sufficient to meet total nursing needs and which are in accordance with the patient plan of care. Each patient receives treatments, medications, and diet as prescribed, and is kept comfortable, clean, well-groomed, and protected from accident, injury, and infection.
- (2) Each shift must include a registered nurse who provides direct patient care.
- (b) Standard: Disaster preparedness. The hospice has an acceptable written plan, periodically rehearsed with staff, with procedures to be followed in the event of an internal or external disaster and for the care of casualties (patients and personnel) arising from such disasters.
- (c) Standard: Health and safety laws. The hospice must meet all Federal, State, and local laws, regulations, and codes pertaining to health and safety, such as provisions regulating--
  - (1) Construction, maintenance, and equipment for the hospice;
  - (2) Sanitation;
  - (3) Communicable and reportable diseases; and
  - (4) Post mortem procedures.
- (d) Standard: Fire protection. (1) Except as provided in paragraphs (d) (2) and (3) of this section, the hospice must meet the provisions of the 1985 edition of the Life Safety Code

of the National Fire Protection Association (which is incorporated by reference)<sup>1</sup> that are applicable to hospices.

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\1\ See footnote to Sec. 405.1134(a) of this chapter.

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(2) In consideration of a recommendation by the State survey agency, HCFA may waive, for periods deemed appropriate, specific provisions of the Life Safety Code which, if rigidly applied would result in unreasonable hardship for the hospice, but only if the waiver would not adversely affect the health and safety of the patients.

(3) Any hospice that, on May 9, 1988, complies with the requirements of the 1981 edition of the Life Safety Code, with or without waivers, will be considered to be in compliance with this standard, as long as the hospice continues to remain in compliance with that edition of the Life Safety Code.

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(4) Any facility of two or more stories that is not of fire resistive construction and is participating on the basis of a waiver of construction type or height, may not house blind, nonambulatory, or physically handicapped patients above the street-level floor unless the facility--

(i) Is one of the following construction types (as defined in the Life Safety Code):

(A) Type II (1, 1, 1)--protected non-combustible.

(B) Fully sprinklered Type II (0, 0, 0)--non-combustible.

(C) Fully sprinklered Type III (2, 1, 1)--protected ordinary.

(D) Fully sprinklered Type V (1, 1, 1)--protected wood frame; or

(ii) Achieves a passing score on the Fire Safety Evaluation System (FSES).

(e) Standard: Patient areas. (1) The hospice must design and equip areas for the comfort and privacy of each patient and family members.

(2) The hospice must have--

(i) Physical space for private patient/family visiting;

(ii) Accommodations for family members to remain with the patient throughout the night;

(iii) Accommodations for family privacy after a patient's death; and

(iv) Decor which is homelike in design and function.

(3) Patients must be permitted to receive visitors at any hour, including small children.

(f) Standard: Patient rooms and toilet facilities. Patient rooms are designed and equipped for adequate nursing care and the comfort and privacy of patients.

(1) Each patient's room must--

- (i) Be equipped with or conveniently located near toilet and bathing facilities;
  - (ii) Be at or above grade level;
  - (iii) Contain a suitable bed for each patient and other appropriate furniture;
  - (iv) Have closet space that provides security and privacy for clothing and personal belongings;
  - (v) Contain no more than four beds;
  - (vi) Measure at least 100 square feet for a single patient room or 80 square feet for each patient for a multipatient room; and
  - (vii) Be equipped with a device for calling the staff member on duty.
- (2) For an existing building, HCFA may waive the space and occupancy requirements of paragraphs (f)(1) (v) and (vi) of this section for as long as it is considered appropriate if it finds that--
- (i) The requirements would result in unreasonable hardship on the hospice if strictly enforced; and
  - (ii) The waiver serves the particular needs of the patients and does not adversely affect their health and safety.
- (g) Standard: Bathroom facilities. The hospice must--
- (1) Provide an adequate supply of hot water at all times for patient use; and
  - (2) Have plumbing fixtures with control valves that automatically regulate the temperature of the hot water used by patients.
- (h) Standard: Linen. The hospice has available at all times a quantity of linen essential for proper care and comfort of patients. Linens are handled, stored, processed, and transported in such a manner as to prevent the spread of infection.
- (i) Standard: Isolation areas. The hospice must make provision for isolating patients with infectious diseases.
- (j) Standard: Meal service, menu planning, and supervision. The hospice must--
- (1) Serve at least three meals or their equivalent each day at regular times, with not more than 14 hours between a substantial evening meal and breakfast;
  - (2) Procure, store, prepare, distribute, and serve all food under sanitary conditions;
  - (3) Have a staff member trained or experienced in food management or nutrition who is responsible for--
- (i) Planning menus that meet the nutritional needs of each patient, following the orders of the patient's physician and, to the extent medically possible, the recommended dietary allowances of the Food and Nutrition Board of the National Research Council, National Academy of Sciences (Recommended Dietary Allowances (9th ed., 1981) is available from the Printing and Publications Office, National Academy of Sciences, Washington, DC 20418); and

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- (ii) Supervising the meal preparation and service to ensure that the menu plan is

followed; and

(4) If the hospice has patients who require medically prescribed special diets, have the menus for those patients planned by a professionally qualified dietitian and supervise the preparation and serving of meals to ensure that the patient accepts the special diet.

(k) Standard: Pharmaceutical services. The hospice provides appropriate methods and procedures for the dispensing and administering of drugs and biologicals. Whether drugs and biologicals are obtained from community or institutional pharmacists or stocked by the facility, the facility is responsible for drugs and biologicals for its patients, insofar as they are covered under the program and for ensuring that pharmaceutical services are provided in accordance with accepted professional principles and appropriate Federal, State, and local laws.

(See Sec. 405.1124(g), (h), and (i) of this chapter.)

(1) Licensed pharmacist. The hospice must--

(i) Employ a licensed pharmacist; or

(ii) Have a formal agreement with a licensed pharmacist to advise the hospice on ordering, storage, administration, disposal, and recordkeeping of drugs and biologicals.

(2) Orders for medications. (i) A physician must order all medications for the patient.

(ii) If the medication order is verbal--

(A) The physician must give it only to a licensed nurse, pharmacist, or another physician; and

(B) The individual receiving the order must record and sign it immediately and have the prescribing physician sign it in a manner consistent with good medical practice.

(3) Administering medications. Medications are administered only by one of the following individuals:

(i) A licensed nurse or physician.

(ii) An employee who has completed a State-approved training program in medication administration.

(iii) The patient if his or her attending physician has approved.

(4) Control and accountability. The pharmaceutical service has procedures for control and accountability of all drugs and biologicals throughout the facility. Drugs are dispensed in compliance with Federal and State laws. Records of receipt and disposition of all controlled drugs are maintained in sufficient detail to enable an accurate reconciliation. The pharmacist determines that drug records are in order and that an account of all controlled drugs is maintained and reconciled.

(5) Labeling of drugs and biologicals. The labeling of drugs and biologicals is based on currently accepted professional principles, and includes the appropriate accessory and cautionary instructions, as well as the expiration date when applicable.

(6) Storage. In accordance with State and Federal laws, all drugs and biologicals are stored in locked compartments under proper temperature controls and only authorized personnel have access to the keys. Separately locked compartments are provided for storage of controlled drugs listed in Schedule II of the Comprehensive Drug Abuse Prevention & Control Act of 1970 and other drugs subject to abuse, except under single unit package drug distribution systems in which the quantity stored is minimal and a

missing dose can be readily detected. An emergency medication kit is kept readily available.

(7) Drug disposal. Controlled drugs no longer needed by the patient are disposed of in compliance with State requirements. In the absence of State requirements, the pharmacist and a registered nurse dispose of the drugs and prepare a record of the disposal.

[48 FR 56026, Dec. 16, 1983; 48 FR 57282, Dec. 29, 1983; 49 FR 23010, June 1, 1984, as amended at 53 FR 11509, Apr. 7, 1988; 55 FR 50835, Dec. 11, 1990]  
[CITE: 42CFR418.200]

[Page 703-704]

#### Subpart F--Covered Services

##### Sec. 418.200 Requirements for coverage.

To be covered, hospice services must meet the following requirements. They must be reasonable and necessary for the palliation or management of the terminal illness as well as related conditions. The individual must elect hospice care in accordance with Sec. 418.24 and a plan of care must be established as set forth in Sec. 418.58 before services

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are provided. The services must be consistent with the plan of care. A certification that the individual is terminally ill must be completed as set forth in Sec. 418.22.

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#### Subpart F--Covered Services

##### Sec. 418.202 Covered services.

All services must be performed by appropriately qualified personnel, but it is the nature of the service, rather than the qualification of the person who provides it, that determines the coverage category of the service. The following services are covered hospice

services:

- (a) Nursing care provided by or under the supervision of a registered nurse.
- (b) Medical social services provided by a social worker under the direction of a physician.
- (c) Physicians' services performed by a physician as defined in Sec. 410.20 of this chapter except that the services of the hospice medical director or the physician member of the interdisciplinary group must be performed by a doctor of medicine or osteopathy.
- (d) Counseling services provided to the terminally ill individual and the family members or other persons caring for the individual at home. Counseling, including dietary counseling, may be provided both for the purpose of training the individual's family or other caregiver to provide care, and for the purpose of helping the individual and those caring for him or her to adjust to the individual's approaching death.
- (e) Short-term inpatient care provided in a participating hospice inpatient unit, or a participating hospital or SNF, that additionally meets the standards in Sec. 418.202 (a) and (e) regarding staffing and patient areas. Services provided in an inpatient setting must conform to the written plan of care. Inpatient care may be required for procedures necessary for pain control or acute or chronic symptom management.

Inpatient care may also be furnished as a means of providing respite for the individual's family or other persons caring for the individual at home. Respite care must be furnished as specified in Sec. 418.98(b). Payment for inpatient care will be made at the rate appropriate to the level of care as specified in Sec. 418.302.

(f) Medical appliances and supplies, including drugs and biologicals. Only drugs as defined in section 1861(t) of the Act and which are used primarily for the relief of pain and symptom control related to the individual's terminal illness are covered. Appliances may include covered durable medical equipment as described in Sec. 410.38 of this chapter as well as other self-help and personal comfort items related to the palliation or management of the patient's terminal illness. Equipment is provided by the hospice for use in the patient's home while he or she is under hospice care. Medical supplies include those that are part of the written plan of care.

(g) Home health aide services furnished by qualified aides as designated in Sec. 418.94 and homemaker services. Home health aides may provide personal care services as defined in Sec. 409.45(b) of this chapter. Aides may perform household services to maintain a safe and sanitary environment in areas of the home used by the patient, such as changing bed linens or light cleaning and laundering essential to the comfort and cleanliness of the patient. Aide services must be provided under the general supervision of a registered nurse. Homemaker services may include assistance in maintenance of a safe and healthy environment and services to enable the individual to carry out the treatment plan.

(h) Physical therapy, occupational therapy and speech-language pathology services in addition to the services described in Sec. 409.33 (b) and (c) of this chapter provided for purposes of symptom control or to enable the patient to maintain activities of daily living

and basic functional skills.

[48 FR 56026, Dec. 16, 1983, as amended at 51 FR 41351, Nov. 14, 1986;  
55 FR 50835, Dec. 11, 1990; 59 FR 65498, Dec. 20, 1994]

[Page 704-705]

Sec. 418.204 Special coverage requirements.

(a) Periods of crisis. Nursing care may be covered on a continuous basis for as much as 24 hours a day during periods of crisis as necessary to maintain an individual at home. Either homemaker or home health aide services or both may be covered on a 24-hour continuous basis during periods of crisis but care during these periods must be predominantly nursing care. A period of crisis is a period in which the individual requires continuous care to achieve palliation or management of acute medical symptoms.

(b) Respite care. (1) Respite care is short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons caring for the individual.

(2) Respite care may be provided only on an occasional basis and may not be reimbursed for more than five consecutive days at a time.

(c) Bereavement counseling. Bereavement counseling is a required hospice service but it is not reimbursable.

[48 FR 56026, Dec. 16, 1983, as amended at 55 FR 50835, Dec. 11, 1990]

[CITE: 42CFR418.301]

[Page 705]

Subpart G--Payment for Hospice Care

Sec. 418.301 Basic rules.

(a) Medicare payment for covered hospice care is made in accordance with the method set forth in Sec. 418.302.

(b) Medicare reimbursement to a hospice in a cap period is limited to a cap amount specified in Sec. 418.309.

[48 FR 56026, Dec. 16, 1983, as amended at 56 FR 26919, June 12, 1991]  
[Page 705]

Sec. 418.301 Basic rules.

- (a) Medicare payment for covered hospice care is made in accordance with the method set forth in Sec. 418.302.
- (b) Medicare reimbursement to a hospice in a cap period is limited to a cap amount specified in Sec. 418.309.

[48 FR 56026, Dec. 16, 1983, as amended at 56 FR 26919, June 12, 1991]

[Page 706-707]

Sec. 418.304 Payment for physician services.

- (a) The following services performed by hospice physicians are included in the rates described in Sec. 418.302:
  - (1) General supervisory services of the medical director.
  - (2) Participation in the establishment of plans of care, supervision of care and services, periodic review and updating of plans of care, and establishment of governing policies by the physician member of the interdisciplinary group.
- (b) For services not described in paragraph (a) of this section, a specified Medicare contractor pays the hospice an amount equivalent to 100 percent of the physician's reasonable charge for those physician services furnished by hospice employees or under arrangements with the hospice. Reimbursement for these physician services is included in the amount subject to the hospice payment limit described in Sec. 418.309. Services furnished voluntarily by physicians are not reimbursable.

(c) Services of the patient's attending physician, if he or she is not an employee of the hospice or providing services under arrangements with the hospice, are not considered hospice services and are not included in the amount subject to the hospice payment limit described in Sec. 418.309. These services are paid by the carrier under the procedures in subparts D or E, part 405 of this chapter.

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Sec. 418.306 Determination of payment rates.

(a) Applicability. HCFA establishes payment rates for each of the categories of hospice care described in Sec. 418.302(b). The rates are established using the methodology described in section 1814(i)(1)(C) of the Act.

(b) Payment rates. The payment rates for routine home care and other services included in hospice care are as follows:

(1) The following rates, which are 120 percent of the rates in effect on September 30, 1989, are effective January 1, 1990 through September 30, 1990 and October 21, 1990 through December 31, 1990:

Routine home care ... ..	\$75.80
Continuous home care:	
Full rate for 24 hours ... ..	442.40
Hourly rate ... ..	18.43
Inpatient respite care ... ..	78.40
General inpatient care ... ..	337.20

(2) Except for the period beginning October 21, 1990, through December 31, 1990, the payment rates for routine home care and other services included in hospice care for Federal fiscal years 1991, 1992, and 1993 and those that begin on or after October 1, 1997, are the payment rates in effect under this paragraph during the previous fiscal year increased by the market basket percentage increase as defined in section 1886(b)(3)(B)(iii) of the Act, otherwise applicable to discharges occurring in the fiscal year. The payment rates for the period beginning October 21, 1990, through December 31, 1990, are the same as those shown in paragraph (b)(1) of this section.

(3) For Federal fiscal years 1994 through 1997, the payment rate is the payment rate in effect during the previous fiscal year increased by a factor equal to the market basket

percentage increase minus--

- (i) 2 percentage points in FY 1994;
- (ii) 1.5 percentage points in FYs 1995 and 1996; and
- (iii) 0.5 percentage points in FY 1997.

(c) Adjustment for wage differences. HCFA will issue annually, in the Federal Register, a hospice wage index based on the most current available HCFA hospital wage data, including any changes to the definitions of Metropolitan Statistical Areas. The payment rates established by HCFA are adjusted by the intermediary to reflect local differences in wages according to the revised wage index.

(d) Federal Register notices. HCFA publishes as a notice in the Federal Register any proposal to change the methodology for determining the payment rates.

[56 FR 26919, June 12, 1991, as amended at 59 FR 26960, May 25, 1994; 62 FR 42882, Aug. 8, 1997]  
[Page 707]

#### Sec. 418.307 Periodic interim payments.

Subject to the provisions of Sec. 413.64(h) of this chapter, a hospice may elect to receive periodic interim payments (PIP) effective with claims received on or after July 1, 1987. Payment is made biweekly under the PIP method unless the hospice requests a longer fixed interval (not to exceed one month) between payments. The biweekly interim payment amount is based on the total estimated Medicare payments for the reporting period (as described in Secs. 418.302-418.306). Each payment is made 2 weeks after the end of a biweekly period of service as described in Sec. 413.64(h)(5) of this chapter. Under certain circumstances that are described in Sec. 413.64(g) of this chapter, a hospice that is not receiving PIP may request an accelerated payment.

[59 FR 36713, July 19, 1994]  
[Page 707-708]

#### Sec. 418.308 Limitation on the amount of hospice payments.

(a) Except as specified in paragraph (b) of this section, the total Medicare payment to a hospice for care furnished during a cap period is limited by the hospice cap amount specified in Sec. 418.309.

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- (b) Until October 1, 1986, payment to a hospice that began operation before January 1, 1975 is not limited by the amount of the hospice cap specified in Sec. 418.309.
- (c) The intermediary notifies the hospice of the determination of program reimbursement at the end of the cap year in accordance with procedures similar to those described in Sec. 405.1803 of this chapter.
- (d) Payments made to a hospice during a cap period that exceed the cap amount are overpayments and must be refunded.

[48 FR 56026, Dec. 16, 1983; 48 FR 57282, Dec. 29, 1983]

[Page 708]

Sec. 418.309 Hospice cap amount.

The hospice cap amount is calculated using the following procedures:

- (a) The cap amount is \$6,500 per year and is adjusted for inflation or deflation for cap years that end after October 1, 1984, by using the percentage change in the medical care expenditure category of the Consumer Price Index (CPI) for urban consumers that is published by the Bureau of Labor Statistics. This adjustment is made using the change in the CPI from March 1984 to the fifth month of the cap year. The cap year runs from November 1 of each year until October 31 of the following year.
- (b) Each hospice's cap amount is calculated by the intermediary by multiplying the adjusted cap amount determined in paragraph (a) of this section by the number of Medicare beneficiaries who elected to receive hospice care from that hospice during the cap period. For purposes of this calculation, the number of Medicare beneficiaries includes--
  - (1) Those Medicare beneficiaries who have not previously been included in the calculation of any hospice cap and who have filed an election to receive hospice care, in accordance with Sec. 418.24, from the hospice during the period beginning on September 28 (35 days before the beginning of the cap period) and ending on September 27 (35 days before the end of the cap period).
  - (2) In the case in which a beneficiary has elected to receive care from more than one hospice, each hospice includes in its number of Medicare beneficiaries only that fraction which represents the portion of a patient's total stay in all hospices that was spent in that

hospice. (The hospice can obtain this information by contacting the intermediary.)  
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#### Sec. 418.310 Reporting and recordkeeping requirements.

Hospices must provide reports and keep records as the Secretary determines necessary to administer the program.  
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#### Sec. 418.311 Administrative appeals.

A hospice that believes its payments have not been properly determined in accordance with these regulations may request a review from the intermediary or the Provider Reimbursement Review Board (PRRB) if the amount in controversy is at least \$1,000 or \$10,000, respectively. In such a case, the procedure in 42 CFR part 405, subpart R, will be followed to the extent that it is applicable. The PRRB, subject to review by the Secretary under Sec. 405.1874 of this chapter, shall have the authority to determine the issues raised. The methods and standards for the calculation of the payment rates by HCFA are not subject to appeal.  
[Page 708-709]

#### Subpart H--Coinsurance

#### Sec. 418.400 Individual liability for coinsurance for hospice care.

An individual who has filed an election for hospice care in accordance with Sec. 418.24 is liable for the following coinsurance payments. Hospices may charge individuals the applicable coinsurance amounts.

(a) Drugs and biologicals. An individual is liable for a coinsurance payment for each palliative drug and biological prescription furnished by the hospice while the individual is not an inpatient. The amount of coinsurance for each prescription approximates 5 percent of the cost of the drug or biological to the hospice determined in accordance with the drug copayment schedule established by the hospice, except that the amount of coinsurance for each prescription may not exceed \$5. The cost of the drug or biological may not exceed what a prudent buyer would pay in similar circumstances.  
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The drug copayment schedule must be reviewed for reasonableness and approved by the

intermediary before it is used.

(b) Respite care. (1) The amount of coinsurance for each respite care day is equal to 5 percent of the payment made by HCFA for a respite care day.

(2) The amount of the individual's coinsurance liability for respite care during a hospice coinsurance period may not exceed the inpatient hospital deductible applicable for the year in which the hospice coinsurance period began.

(3) The individual hospice coinsurance period--

(i) Begins on the first day an election filed in accordance with Sec. 418.24 is in effect for the beneficiary; and

(ii) Ends with the close of the first period of 14 consecutive days on each of which an election is not in effect for the beneficiary.

[Page 709]

Sec. 418.402 Individual liability for services that are not considered hospice care.

Medicare payment to the hospice discharges an individual's liability for payment for all services, other than the hospice coinsurance amounts described in Sec. 418.400, that are considered covered hospice care (as described in Sec. 418.202). The individual is liable for the Medicare deductibles and coinsurance payments and for the difference between the reasonable and actual charge on unassigned claims on other covered services that are not considered hospice care. Examples of services not considered hospice care include: Services furnished before or after a hospice election period; services of the individual's attending physician, if the attending physician is not an employee of or working under an arrangement with the hospice; or Medicare services received for the treatment of an illness or injury not related to the individual's terminal condition.

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Sec. 418.405 Effect of coinsurance liability on Medicare payment.

The Medicare payment rates established by HCFA in accordance with Sec. 418.306 are not reduced when the individual is liable for coinsurance payments. Instead, when establishing the payment rates, HCFA offsets the estimated cost of services by an estimate of average coinsurance amounts hospices collect.

[56 FR 26919, June 12, 1991]

[The above law is as posted at the Government Printing Office Website at:  
[www.access.gpo.gov/nara/cfr/waisidx\\_00/42cfr418\\_00.html](http://www.access.gpo.gov/nara/cfr/waisidx_00/42cfr418_00.html)

[Revised as of October 1, 2000]

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SAMPLE COMPLAINT FORM

U.S. Mail certified no. \_\_\_\_\_  
(Sent certified and return receipt mail)

To: (name & address \_\_\_\_\_  
of government agency) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

From: (name/address \_\_\_\_\_  
of person(s) making \_\_\_\_\_  
complaint) \_\_\_\_\_  
\_\_\_\_\_

(Home tel. No.) \_\_\_\_\_  
(Work tel. no.) \_\_\_\_\_  
Date complaint sent: \_\_\_\_\_

Re: Name of hospice \_\_\_\_\_  
(Address of hospice) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Tel. no. of hospice: \_\_\_\_\_  
Re: name of patient \_\_\_\_\_  
Patient date of birth: \_\_\_\_\_  
Patient's hospice ID. no. \_\_\_\_\_  
(Medical record no. If known)  
Date patient admitted \_\_\_\_\_  
(to hospice)  
Date patient discharged from hospice: \_\_\_\_\_  
(Date of discharge/death)

Terminal diagnosis: \_\_\_\_\_

Exact location (address and room) where problem(s) occurred:

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Number of total pages in this complaint: \_\_\_\_\_

Page one of three

Attending physician: \_\_\_\_\_

Physician address: \_\_\_\_\_

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Physician tel. no. \_\_\_\_\_

Name of hospice RN \_\_\_\_\_

(Case manager)

Number of separate complaints/problems (allegations) to government agency: \_\_\_\_ (numeral) \_\_\_\_\_ (spelled out)

1. Brief description of complaint problem/allegation number 1:

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Approximate date(s) this problem occurred: \_\_\_\_\_

A more detailed description is attached: Yes \_\_\_\_ No \_\_\_\_

2. Brief description of complaint problem/allegation number 2:

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Approximate date(s) this problem occurred: \_\_\_\_\_

A more detailed description is attached: Yes \_\_\_\_ No \_\_\_\_

3. Brief description of complaint problem/allegation number 3:

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Approximate date(s) this problem occurred: \_\_\_\_\_

A more detailed description is attached: Yes \_\_\_\_ No \_\_\_\_

Page two of three

4. Brief description of complaint problem/allegation number 4:

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Approximate date(s) this problem occurred: \_\_\_\_\_

A more detailed description is attached: Yes \_\_\_\_\_ No \_\_\_\_\_

5. Brief description of complaint problem/allegation number 5:

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There are more than five (5) problem areas and additional descriptions of other problems are attached: Yes \_\_\_\_ No \_\_\_\_\_

The number of additional problems is: \_\_\_\_\_

The total number of complaint/problem areas to be investigated is: \_\_\_\_\_.

\_\_\_\_\_ Date signed: \_\_\_\_\_  
(Signature(s) of person(s)  
making complaint)

\_\_\_\_\_ Date signed: \_\_\_\_\_  
(Signature of person  
making complaint)

\_\_\_\_\_ Date signed: \_\_\_\_\_  
(Signature of person  
making complaint)  
Page three of three

(Keep a copy of this complaint for your records!)

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## ENDNOTES

1. See *The Washington Post* article, June 14, 1998, page A1 & A16, "HOSPICES BIG BUSINESS, THANKS TO MEDICARE ... Exploitation of Some Patients is Alleged" by Charles R. Babcock, staff writer.
2. See U.S. Office Of Inspector General's "Draft Compliance Program Guidance for the Hospice Industry" dated July 19, 1999 and published in the U.S. Federal Register. Hospice compliance programs are "designed to establish a culture within a hospice that promotes prevention, detection, and resolution of instances of conduct that do not conform to Federal and State law [i.e.: "illegal"], and Federal, State, and private payor health care program requirements, as well as the hospice's business policies. (From p. 1).
3. See United States Code of Federal Regulations 42 CFR 418.22(b). For actual wording of this law see the Section on "State and Federal Law Governing Hospice" in this text. The descriptions of what hospice is "supposed to" provide are based on the uniform standards set forth in the United States Code of Federal Regulations.
4. To see the standards of care, please refer to the Code of Federal Regulations cited in the Section "State and Federal Law Governing Hospice" in this text.
5. Hospices which are licensed by the state and certified by Medicare to participate in the Medicare program must meet uniform standards of care which are set forth in the Federal Code of Federal Regulations, Title 42 - Public Health, chapter IV - Health Care Financing Administration, Department of Health and Human Services, Part 418 - HOSPICE CARE. When referring to these laws, the following abbreviation is used: 42 CFR 418.00 - 418.405. These standards of care are the laws that must be followed by all licensed and certified hospices and contain descriptions of the types of services which must be provided to you. We provide a copy of these federal laws in the section "State and Federal Law Governing Hospice" in this text. In addition, copies of these laws are available at any metropolitan public library and on the internet. See the section on "Important Links to Other Resources" for Internet addresses.
6. See 42 CFR 418.50.
7. Surveys are usually performed by the state surveyors who are part of your state's health facility licensing and certification division. For any violation of the federal regulations (found at 42 CFR part 418), the surveyor will refer to the specific section of the Code of Federal Regulation. She will also include "Tag numbers" which are used to further separate one type of violation from another. The states usually perform these surveys,

because each state certifies and licenses the hospices which participate in the U.S. Medicare programs or Medicaid programs operating within that state.

8. According to 42 CFR 418.58 the hospice's Plan of Care "must state in detail the scope and frequency of services needed to meet the patient's and family's needs."

9. 42 CFR 418.204 states that, "Nursing care may be covered on a continuous basis for as much as 24 hours a day during periods of crisis as necessary to maintain an individual at home ... .A period of crisis is a period in which the individual requires continuous care to achieve palliation or management of acute medical symptoms." 42 CFR 418.82 states that "Nursing services must be directed and staffed to assure that the nursing needs of patients are met." The hospice must meet your needs for nursing care!

10. Hospice facilities must comply with the uniform standards of care set forth at 42 CFR 418.100, must meet the "total nursing needs" of the patients, and keep the patients "comfortable, clean, well-groomed, and protected from accident, injury, and infection." See the section on State and Federal Laws Governing Hospice in this text for details of these standards. Hospices must meet all requirements of the uniform standards whether the patient is being cared for in his own home, a nursing home, the hospice's own facility or in a hospital.

11. The "attending physician" according to 42 CFR 418.3 is the physician identified by the patient "as having the most significant role in the determination and delivery of the individual's medical care." If you have more than one physician, you must choose one of them to "take charge" of the care you will be receiving and who is willing to give the medical "orders" for all medications, services and equipment you may need. If you are seeing a specialist who has been treating you for the terminal illness, that specialist may be willing to assume the role of the attending physician for you. If not, your "family" doctor may assume this role. In a crisis, the hospice's own medical director may temporarily serve as attending physician until you find another physician to be the "attending physician."

12. The Hospice's Plan of Care for each patient must meet the standards set at 42 CFR 418.58. The plan of care must be adequate to meet the patient's needs and is to be reviewed by the attending physician, the hospice's medical director and all the members of the Interdisciplinary Team who are together responsible for establishing the plan of care.

13. For federal Guidelines regarding hospice social worker services, see: 42 CFR ch. iv. Part 418.68, 418.84, 418.88, 418.202(d).

14. See 42 CFR 418.88(a) regarding Bereavement services (See the Section on State and Federal Law Governing Hospice in this text). Whether the patient resided in a facility or passed away in his own home, the hospice is required to provide bereavement counseling even if the patient was in the facility for one day or six months.

15. Federal regulations at 42 CFR Section 418.24 and 418.28 explain how a patient may "elect" (choose) the hospice "benefit and "revoke" (give up) the hospice benefit. See federal regulations and standards of care in this text for more details.

16. 42 CFR Section 418.54 of the federal regulations state: "The medical director ... assumes overall responsibility for the medical component of the hospice's patient care program." 42 CFR Section 418.50 states "A hospice must ... make ... drugs ... routinely available on a 24 hour basis; [and] "make ... covered services available ... to the extent necessary to meet the needs of individuals for care that is reasonable and necessary for the palliation and management of terminal illness and related conditions." "Palliation" is the relief of symptoms, and pain management is one of the main symptoms which hospice must focus on relieving.

17. See the Code of Federal Regulations, 42 CFR part 418 which governs hospice. This set of federal regulations is provided herein in the section on "Federal Laws governing Hospice."

18. The Code of Federal Regulations at 42 CFR 418.30 states "An individual or representative may change, once in each election period, the designation of the particular hospice from which hospice care will be received." [emphasis added]

19. The Code of Federal Regulations at 42 CFR chapter iv. Part 418.50 states that "A hospice must maintain compliance with the conditions ... [and] a hospice must ... make nursing services, physician services, and drugs and biologicals routinely available on a 24-hour basis; [and] make all other covered services available on a 24-hour basis to the extent necessary to meet the needs of individuals for care that is reasonable and necessary for the palliation and management of terminal illness and related conditions; and provide these services in a manner consistent with accepted standards of practice." See the section on federal law for the complete laws governing hospice care.

20. Section 418.3 of the Code of Federal Regulations (42 CFR 418.3) states that "Attending physician means a physician who is a doctor of medicine or osteopathy; and is identified by the individual [patient], at the time he or she elects to receive hospice care, as having the most significant role in the determination and delivery of the individual's hospice care." Section 418.58 states that "A written plan of care must be established ... by the Attending physician, the Medical director ... and [the hospice] Interdisciplinary Group ... The plan must ... state in detail the scope and frequency of services needed to meet the patient's and family's needs [emphasis added].

21. Section 418.54 (42 CFR 418.54) states: "The Medical director must be a hospice employee who is a doctor ... who assumes overall responsibility for the medical component of the hospice's patient care program." Any time the medical interventions of the hospice do not meet your loved one's need for symptom management, the medical director is required to get involved and to correct any inadequacies in the care plan, the medical orders and frequency of services needed. The medical director is the second line of defense to assure quality hospice care. However, not all hospice medical directors fulfill this protective role.

22. The U.S. Code of Federal Regulations (42 CFR Section 418.82) states: "The hospice must provide nursing care and services by or under the supervision of a registered nurse.  
a) Nursing services must be directed and staffed to assure that the nursing needs of patients are met ... . [emphasis added]  
c) Services must be provided in accordance with recognized standards of practice."

23. The U.S. Code of Federal Regulations (42 CFR Section 418.94) states: "Home health aide and homemaker services must be available and adequate in frequency to meet the needs of the patients ... .A registered nurse must visit the home site at least every two weeks when aide services are being provided, and the visit must include an assessment of the aide services."

24. The U.S. Code of Federal Regulations (42 CFR Section 418.96, subpart c) states: " ... drugs and biologicals are administered only by the following individuals: (1) A licensed nurse or physician, (2) An employee who has completed a State-approved training program in medication administration, (3) The patient if his or her attending physician has approved. (4) Any other individual in accordance with applicable state and local laws. The persons, and each drug and biological they are authorized to administer, must be specified in the patient's plan of care."

25. The Code of Federal Regulations states (at 42 CFR 418.62) that, "A hospice must demonstrate respect for an individual's rights by ensuring that an informed consent form that specifies the type of care and services that may be provided as hospice care during the course of the illness has been obtained for every individual, either from the individual or representative [who is authorized under state law to make decisions for a patient who is physically or mentally incapacitated] ... ."

The Informed Consent Form is one of the documents that you must sign in order to be admitted to a hospice program. Please make sure that the hospice representative explains ALL services you may be entitled to and which they provide ... BEFORE YOU SIGN ON THE DOTTED LINE. Getting your signature on the form is the hospice's legal proof to the government that it has actually provided "informed consent" to you. Actually fully informing you and your family is the implication of this federal regulation protecting your rights.

26. The Code of Federal Regulations at 42 CFR 418.50(b) makes it a Condition of Participation that "A hospice must ... make all ... covered services available on a 24-hour basis to the extent necessary to meet the needs of individuals for care that is reasonable and necessary for the palliation and management of terminal illness and related conditions." [emphasis added].

27. The Code of Federal Regulations at 42 CFR 418.58© states "The plan must include an assessment of the individual's needs and identification of the services including the management of discomfort and symptom relief. It must state in detail the scope and frequency of services needed to meet the patient's and family's needs." [emphasis added].

28. The Code of Federal Regulations at 42 CFR 418.88 states "Counseling services must be available to both the individual and the family. Counseling includes bereavement counseling, provided after the patient's death as well as dietary, spiritual and any other counseling services for the individual and family provided while the individual is enrolled in the hospice ... There must be an organized program for the provision of bereavement services ... [which] should reflect family needs ... up to one year following the death of the patient." [Emphasis added]