



ALEXIAN
BROTHERS
Health System



Guide To

End-of-Life Issues



Alexian Brothers Health System carries out the healing mission of the Catholic Church through the Alexian Brothers Ministries by identifying and developing effective responses to the health and housing needs of those we are called to serve.

Alexian Brothers Health System

Guide To End-of-Life Issues



Developed by the Quality of Life Committee
of the Alexian Brothers of Missouri



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Foreword

While many people fear how they will die more than death itself, most do not plan for the kind of physical, emotional, or spiritual care they will want at the end of their life. Even though death and dying are uncomfortable subjects for most of us, we need to plan for our death so that it will be on our terms and reflect our needs and values.

Now that medical technology offers us so many ways of prolonging life, the process of dying and making end-of-life decisions has become even more difficult. Further, the process of dying is made more complex by a person's expectations about how they will die and what meaning there is in their death. These difficulties can best be met when the dying person and their caregivers are well-informed.

The Alexian Brothers of Missouri, through a grant from The Incarnate Word Foundation, have developed this "Guide to End-of-Life Issues," to help individuals and their families identify and achieve their own end-of-life goals in harmony with their personal, cultural, and spiritual understanding.

This guide reflects our belief that the quality of one's death is as important as the quality of one's life.

*The Quality of Life Committee
of the Alexian Brothers of Missouri*



INTRODUCTION:

Death Is Not Easy To Talk About

For many, discussing end-of-life issues is uncomfortable, difficult, maybe even frightening. This is especially true as a loved one begins the dying process. At this time, family members often find it difficult to know just what to say to the dying person or to one another, or where to turn for answers to their questions about dying and death itself.

This guide is designed to help those who are dying, their families and friends and health care professionals better understand what happens when someone dies. It discusses all aspects of the dying process from the needs of the dying person, to the needs of those close to them during and after by:

- Identifying physical, emotional, social and spiritual end-of-life care issues,
- Addressing individual, family member and caregiver questions regarding end-of-life care,
- Providing guidelines for end-of-life decision-making,
- Describing the dying process,
- Identifying available resources and support systems, and
- Providing help with the grieving process.

At this time, family members often find it difficult to know just what to say to the dying person or to one another ...

The journey you will take with his guide will be challenging and it may bring up emotions and feelings that will be uncomfortable. It is our hope that coming face-to-face with these issues will better prepare you for the challenges that death, the final passage of life, will bring.

Advance Care Planning

We make plans for our future every day: where to spend our vacations, where to send our children to school, where to live when we retire, and how to pay for it all. We plan for occasions we look forward to, as well as situations we hope to avoid. Yet, too often we do not make plans for the end of our life, or for a time when we may be too sick to talk or make decisions for ourselves.

Advance care planning is less about how we choose to die than about how we choose to live. It is a gift one gives to their family and loved ones - a gift of understanding about the values and beliefs that one holds dear. Individuals and their families should be able to trust that the care they receive at the end of their lives is not only of high quality, but also that it respects their desires for peace, autonomy and dignity.

Questions to Ask for Advance Care Planning

Advance care planning includes answering important questions such as:

- If you couldn't speak for yourself who would you trust to make your health care decisions?
- What do you fear most about illness and death?
- Where do you want to be at the end of your life – at home, in a hospital, or in a nursing care facility?
- If you choose to die at home, can your family or friends provide the kind of care you will need or will you need the help of professionals?
- Should medical technology be used to keep you alive as long as possible?
(Would your answer change if you were older or had a terminal condition?)

Eight Things To Do for Advance Care Planning

- 1** Get facts about your condition and discuss your health care options with your doctor and other health care providers.
- 2** Think about life and what is important to you - what kind of care you would and would not want at the end of your life.
- 3** Receive spiritual support from your faith community leader.
- 4** Seek estate planning, legal and administrative information from your lawyer, accountant, financial advisor, or family members.
- 5** Organize your affairs by recording the location of important documents, funeral arrangements, names of people to be contacted on your death and the distribution of personal possessions.
- 6** Discuss your life goals and values with those you love.
- 7** Make choices, and make certain your loved ones and your health care providers understand them.
- 8** Be sure your advance care planning decisions are written clearly and on file in your medical chart. Bring a copy to your hospital where you are a patient and give copies to your family or appointed guardian.

Medical Legal Documentation

Advance Directives

It is one's right to accept or refuse medical care. Advance directives protect this right if one is physically or mentally unable to choose or communicate one's wishes. Not only do they protect one's right to make medical choices for one's self, they help family members make difficult decisions and provide guidelines for one's physician. It is best to write them before you face a terminal diagnosis. Place copies with your doctor, hospital, family members, or surrogate. (Do not place them in a safe deposit box which is sealed when one dies.) There are two types of advance directives. You may use one or both:

Durable Power of Attorney for Health Care - Names a person you wish to make health care decisions when you can no longer speak for yourself.

Living Will - A written document that tells others what kind of life-sustaining treatment you want or do not want when death is imminent.

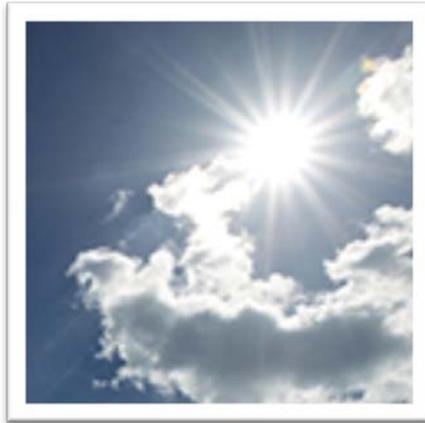
Each state has some specific regulations on advance directives. *(If you live in more than one state you will need advance directives for each state.)* Some states require notary signatures, or have rules concerning where advance directives are to be stored - others do not. Policies and formats may vary. Current advance directive forms for each state can be obtained by calling Partnership for Caring at Choice in Dying: (800)-989-9455.

It is one's right to accept or refuse medical care.

Durable Power of Attorney for Health Care

- This document lets you name another person (surrogate/health care proxy) to make medical decisions for you.
- This document is not legally binding unless it is completed properly and witnessed according to the laws of your state.
- It must be signed while you are competent.
- Your surrogate can speak for you, if and only if, you can't state your wishes yourself.

(A sample durable power of attorney document is included as the last four pages of this document.)



Living Will

- A written document that explains what medical treatment(s) you want or do not want.
- It takes effect only when one is no longer able to speak for oneself.
- It applies only if one suffers from a terminal or irreversible condition.
- Copies of one's Living Will should be given to one's physician, hospital, nursing facility, family members, religious leader, attorney, or surrogate.
- A person can revoke/change his/her Living Will at any time and in any manner.

(This Generic Living Will found at: <http://www.lectlaw.com>, the website of the Lectric Law Library is not a legal document. It is meant as an example only as it may not be appropriate in the state where you live or reflect your circumstances.)

A Living Will is a written document that explains what medical treatment(s) you want or do not want.

Living Will Example

I, _____, of _____ being of sound mind, do hereby willfully and voluntarily make known my desire that my life not be prolonged under any of the following conditions, and do hereby further declare:

1. If I should, at any time, have an incurable condition caused by any disease or illness, or by any accident or injury; and be determined by any two or more physicians to be in a terminal condition whereby the use of "heroic measures" or the application of life-sustaining procedures would only serve to delay the moment of my death, and where my attending physician has determined that my death is imminent whether or not such "heroic measures" or life-sustaining measures are employed, I direct that such measures and procedures be withheld or withdrawn and that I be permitted to die naturally.
2. In the event of my inability to give directions regarding the application of life-sustaining procedures or the use of "heroic measures," it is my intention that this directive shall be honored by my family and physicians as my final expression of my right to refuse medical and surgical treatment and my acceptance of the consequences of such refusal.
3. I am mentally, emotionally and legally competent to make this directive and I fully understand its import.
4. I reserve the right to revoke this directive at any time.
5. This directive shall remain in force until revoked.

IN WITNESS WHEREOF, I have hereto set my hand and seal this _____ day of _____, 20__

Signed:-----

Declaration of Witnesses

The declarant is personally known to me and I believe him to be of sound mind and emotionally and legally competent to make the herein continued Directive to Physicians. I am not related to the declarant by blood or marriage, nor would I be entitled to any portion of the declarant's estate upon his decease, nor am I an attending physician of the declarant, nor an employee of the attending physician, nor an employee of a health care facility in which the declarant is a patient, nor a patient in a health care facility in which the declarant is a patient, nor am I a person who has any claim against any portion of the estate of the declarant upon his death.

Signed _____

Commonly Asked Questions About Advance Directives:

- **Must one's physician, surrogate and health care institution carry out the wishes expressed in the advance directive?**

Yes. Health care providers and one's surrogate are obligated to honor the wishes as expressed in one's advance directive. If they are unable to comply for religious or moral reasons, they must assist you in finding a caregiver who will.

- **Can one's advance directive for medical treatment or decisions made by one's surrogate be overridden by one's family members?**

No. If one has designated a surrogate, only he/she has the legal authority to make health care decisions for them. However, a surrogate may wish to obtain additional information from your family to assist him/her in making decisions.

- **Do I need an attorney to enact an advance directive or durable power of attorney for health care?**

No. However, it must be completed properly and witnessed according to the laws of your state.

- **Does my advance directive have to be notarized?**

To determine this you will need to check the laws in your state. In Missouri, for example, notarization is required to enact a durable power of attorney for health care decisions while a Living Will only requires two witnesses.

- **When does one's advance directive for medical treatment and durable power of attorney for health care go into effect?**

They go into effect when, and only when one is no longer able to make or communicate one's own decisions. As long as one is able to make decisions, it is both one's right and responsibility to make one's own decisions.

- **What should one consider before writing an advance directive?**

Your desired quality of life, your beliefs and your values.

- **What does code status refer to?**

Code status indicates the status of a patient in a health care facility with respect to their desires for resuscitative effort as expressed formally in documents such as advance directives. For example, if the need should arise for cardiopulmonary resuscitation (CPR), unless the patient specifically requests that they not be resuscitated, CPR will be performed.



Withdrawal of Artificial Life

Support

One of the difficult decisions that family members sometimes have to address is that of withdrawing life support from a loved one. Knowing the individual's wishes ahead of time can facilitate the making of this decision. Clergy /Pastoral Care staff can be especially supportive during this decision-making process.

Get information from your physician about ALL of the ramifications of both withdrawing life support and continuing life support.

Here is a checklist that is helpful to follow when making the decision to withdraw life support.

- 1 Does the patient have a Living Will or a durable power of attorney for health care?
- 2 If yes to the above question, is the proposed decision to withdraw life support in accordance with the wishes expressed in the Living Will?
- 3 Has the referring doctor been notified?
- 4 Has a second physician's opinion been obtained?
- 5 If the patient is capable, has he/she been involved in the decision-making process? If the patient is not capable or unconscious, has the next-of-kin/or surrogate been involved in the decision-making process?
- 6 Has the intensive care unit (ICU) doctor communicated the plan of care to the family?

- 7 Has a Do Not Resuscitate (DNR) order stating that should a person's breathing or heartbeat stop there will be no attempt to revive them been written?
- 8 Has the patient or family had the opportunity to speak to a spiritual resource person?
- 9 Are there any particular religious/cultural practices to be followed at the time of death?
- 10 Have all other active treatments been withdrawn and comfort measures implemented?



Physical, Emotional, Social, and Spiritual End-of-Life Issues

During the process of dying the needs of the whole person - their body, their mind and their spirit must all be considered.

Physical End-of-Life Issues

Questions for the individual to ask as they face physical end-of-life issues:

- Do you want medical treatment, and, if so, what treatment plans do you want in place?
- How much do you want done to support or sustain your life?
- Do you know you have a right to refuse or change your mind about your medical treatment at any time?
- How do you tell your doctor what you want and don't want?
- Do you know that you have a right to die pain-free?

Responding to an Individuals

Physical Needs

Three Categories of Medical Treatments

1 Life Supporting

Life supporting treatment uses Cardiopulmonary Resuscitation (CPR) and a mechanical ventilator to keep one's heart and lungs working when they can no longer function on their own.

- **CPR** is a medical procedure performed when a person no longer has a pulse or the ability to breathe. It is used to maintain circulation and to supply oxygen to the heart, brain, and the rest of the body. The procedure may involve external chest compressions, administration of drugs, or electric shock.
- **Mechanical Ventilator** (respirator) is a machine that breathes for a person by moving air into their lungs when they are unable to breathe naturally.

2 Life Sustaining

Life sustaining care, which involves treatment and machines such as CPR and respirators to prolong your life when your condition cannot be reversed or cured, may also include the following:

- **Artificial Nutrition and Hydration** (tube feedings) is a method of delivering food and water through a tube inserted either directly into the stomach; through the nose or mouth, or into a blood vessel (intravenously).
- **Kidney Dialysis:** a method of cleaning a person's blood by machine when kidneys no longer work properly.

- **Antibiotic Drugs** are administered to fight off an infection.
- **Blood Transfusions** provide blood or blood components to a patient. The blood products used may be the person's own or that of a donor(s).

3 Life Enhancing

Life-enhancing care keeps you comfortable until death occurs naturally. Nothing is done artificially to prolong one's life.

- **Palliative Care** is the comprehensive management of the physical, psychological, social and spiritual needs of both the individual and his/her loved ones. The goal of palliative care is to achieve the best possible quality of life through relief of physical and psychological suffering and control of symptoms. It is especially suited to the care of persons with incurable, progressive illnesses. Palliative care requires an interdisciplinary, team-oriented, individual and family-centered approach to providing quality care at the end of life.
- **Hospice Care** is similar to Palliative Care, but it is administered during the final stages of the dying process. A physician can recommend hospice for a person who probably has less than six months to live. Hospice medical services are limited to pain medication and other comfort care rather than control of symptoms. In signing up for hospice, the individual or their surrogate agrees to waive their rights to curative treatments - though only for conditions relating to their terminal illness. You may leave a hospice and choose curative care at any time. Hospice care may be provided at home, a hospice facility, a hospital, or a nursing home.

Emotional End-Of-Life Issues

Questions to Ask for Emotional End-of-Life Issues:

- Do your family and your care givers know that they have a responsibility to honor your choices and wishes?
- Do you know that you have the right to determine who you want to be with you and support you during the dying process?
- Are you aware that fear is common as one begins to recognize the losses associated with dying?
- Did you know that depression is common when one has a terminal illness?
- What beliefs and values do you hold that should be considered by those making medical decisions for you if you become unable to speak for yourself?
- If you have to choose between living longer and quality of life, how would you approach this balance?
- How do you determine what you want and/or what is best for you?
- Do you realize that you may experience anxiety over what will happen to you because of your illness?

Did you know that depression is common when one has a terminal illness?

Responding to an Individual's Emotional Needs

NEED: The individual needs to know that his/her wishes, desires and preferences regarding the use of medical treatments and technologies will be both listened to and honored.

Fear: The individual's fear is that he/she will not be heard because they will be considered by family members and health care staff to be no longer mentally competent to make their own health care decisions. Many family members and health care staff fear that, at the moment when health care treatment decisions need to be made, the individual will experience a significant change in their cognitive ability either through depression or some form of dementia. This makes it very difficult for family members and health care staff to determine the wishes of the individual.

Response: Family members need to talk with the individual concerning the individual's desires, preferences for health care treatments and use of life-sustaining technologies. Family members need to understand the benefits and liabilities of a Living Will, advance directives, or code status.

NEED: The individual needs to know that their medical needs will be cared for in the dying process.

Fear: The individual is usually more afraid of the physical pain of dying than of death itself.

Response: The health care staff needs to provide active pain management for the individual in the dying process. Family members can be extremely helpful in alerting the health care staff to the physical pain of the individual.

NEED: The individual needs to know that his/her social, emotional and spiritual needs will be cared for in the dying process.

Fear: Most people are afraid of the unknown. They have never been through the dying process and do not know what to expect.

Response: As the dying process begins, family members, clergy, and health care staff can support the individual in the following ways:

- *Talk to the individual and assume that they can hear you.*
- *Share with them what you will miss about them.*
- *Share your fondest memories of the individual with them.*
- *Use familiar prayers or scripture with them.*
- *Sing a familiar song or hymn or recite a favorite poem to them.*
- *Hold their hand or gently touch them on the forehead.*
- *Reassure the individual that it is okay for them to let go.*



Social End-Of-Life Needs

The individual may need:

- Intellectual stimulation,
- Social interaction,
- To go out for a ride in the car,
- To make a visit to their home,
- Memory stimulation through family pictures and reminiscing,
- To replace some of their losses, such as involvement with a religious community, civic or hobby-oriented organization, or social clubs, with activities at home or in a health care facility, and
- Time for quiet reflection to integrate life experiences often makes the difference between the individual feeling despair or hope, depression or acceptance.

Showing the dying person that they belong and are not alone affirms their value as a person and may fend off or alleviate depression.

Responding to an Individual's Social Needs

Meet the dying person's social needs by being with them, letting them know you care about them, or by helping them get to social activities. Showing the dying person that they belong and are not alone affirms their value as a person and may fend off or alleviate depression.

Spiritual End-of-Life Issues

An individual's spirituality, or identified religious belief system, will determine how they cope with and find answers for the following questions:

Questions to Ask for Spiritual End-of-Life Issues

- 1 What do you see as the meaning of your life?
- 2 Do you have any religious or spiritual beliefs that are important to you? (If so, how can these help sustain you at this time in your life?)
- 3 Why am I suffering?
- 4 How will my family and significant others cope with my death?
- 5 What will happen to me after I die?

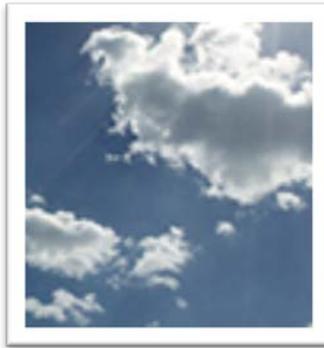
Responding to an Individual's Spiritual Needs

An Individual Needs:

- To believe that life is meaningful and has a purpose,
- To feel a sense of community and deeper relationships,
- To be appreciated and respected,
- To be listened to and be heard,
- To feel that one is growing in faith, and
- To receive practical help in developing a mature faith.

An Individual's Spirituality May Be Enhanced Through:

- Prayer and meditation,
- Reflection or quiet listening to one's heart,
- Communion with nature,
- Music, drama, poetry; dance or art,
- Inner dialogues with one's self or with God, or by journaling,
- Loving relationships with others,
- Service to others in need,
- Forgiveness of others and/or oneself,
- Empathy, compassion or hope,
- Laughter, humor or joy, and
- Participation in religious services, activities and social gatherings.



Managing Pain

and Suffering

Physical pain and mental suffering are often a part of the end-of-life journey.

Physical Pain

When pain is present, the dying person has a right to have their pain properly assessed and treated so they are as pain-free as possible. Since pain cannot be truly "measured" or proven, caregivers must always believe that the pain is very real. Never dismiss, minimize or discount an individual's pain. Because people may have different responses to the many different kinds of pain-relieving medications available today, a variety of options may be needed.

If the individual and their family are educated about pain control it can help the individual achieve an acceptable level. Because many who are dying do not want to admit that they have pain as they believe it is a sign of weakness, or are afraid of complaining, or believe that pain is a normal part of the dying process, good communication between the individual in pain and caregivers is essential. Caregivers can help by encouraging the individual in pain to vocalize the pain: how it hurts, where it hurts, when it hurts, and how much it hurts.

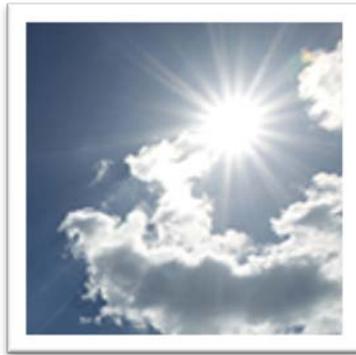
Physical pain and
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journey.

Health care practitioners can help the individual and their family by using The "ABCDE" approach to manage pain.

The "A B C D E" Approach

- A. Ask about pain regularly. Assess pain systematically.
- B. Believe the patient/resident and family in their reports of pain and what relieves it.
- C. Choose pain control options appropriate for the patient, family and setting.
- D. Deliver interventions in a timely, logical, and coordinated fashion.
- E. Empower patients/residents and their families. Enable them to control their course to the greatest extent possible.

The following example of an assessment is another way to evaluate a patient's comfort level that can help patients and families address the type and location of the pain. It also helps to determine what medications have helped to relieve the pain.



Comfort Assessment

Patient Name _____

Medical Record # _____

Date _____ Person Answering Questions _____

Staff Name/Title _____

Pain

1. On the diagram, shade in the areas where you feel pain. Put an X on the area where it hurts most.



2. Please rate your pain by circling the one number that best describes your pain.

At its worst in the past 24 hours

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Ever Pain

Right now

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Ever Pain

3. Indicate the pattern of pain:

Constant

Intermittent

Brief

No Pattern

4. Indicate the character/quality of which applies:

BONE

worse with movement

muscle aching

heavy

dull

steady

tender to pressure

VISCERAL

squeezing

deep

pressing

crushing

cramping

bloating

itching

NERVE

burning

tingling

sharp/shooting

throbbing

numbness

light touch painful

5. What level of pain is acceptable?

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Ever Pain

6. Symptoms other than pain that cause you problems:

shortness of breath

fatigue

anxiety

insomnia

nausea

constipation

other _____

7. Circle the one number that describes how, during the last 24 hours, your symptoms have interfered with your comfort.

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Ever Pain

Intervention

Medication given _____

Date _____ Time _____

1 Hour after administration of medication—patient response:

0 1 2 3 4 5 6 7 8 9 10

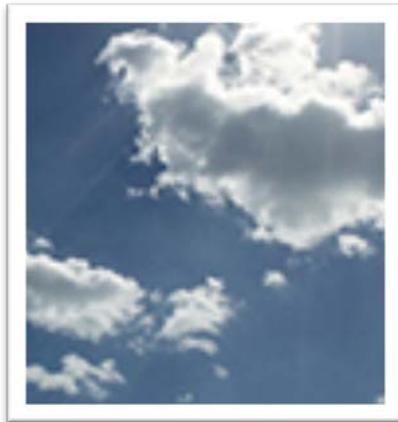
No Pain

Worst Ever Pain

Suffering

The illness taking the patient's life may cause physical pain, but it does not necessarily cause suffering. Suffering is mental anguish and it can occur even though physical pain is not present. It results from a loss or disruption of the sense of self. The dying person may be afraid of losing control; being dependent; being a burden; being separated from their home, family or work; being in pain; depleting family resources to pay for health care; or of leaving things undone. Only by asking the individual if they are suffering will family or health care staff know. Just asking if they are suffering can provide relief. Or, you might be more specific and ask: "What are you afraid of?"

The most effective strategies described by dying people to help relieve suffering or to increase their ability to cope are connecting with people and/or connecting with their spiritual dimension.



Integrative/Alternative Medicine

Integrative/alternative medicine, a blend of conventional medicine and complementary therapies, seeks to balance the body, mind and spirit, and may provide an additional source of comfort. A glossary of some integrative/alternative therapies follows:

Aromatherapy utilizes the "medicinal properties" of very concentrated essential oils extracted from plants through a process of steam distillation or cold pressing. The oils are then mixed with a carrier such as oil or alcohol before use. They may be inhaled, sprayed in the air, rubbed on the skin, or applied as a compress. They are not to be consumed and some may cause problems such as skin irritation or allergic reactions.

Acupuncture stimulates certain points on the surface of the body by inserting needles at specific points on the body. It is used to prevent or modify pain, to normalize physiological functions and to treat diseases or dysfunctions of the body. It is based on the belief that the body contains energy channels or meridians through which qi, a vital life energy, flow.

Acupressure, which is often called "acupuncture without needles," uses pressure from the fingers and hands to stimulate the energy points in the body to remove energy blocks that are believed to produce health problems.

Guided Imagery is a form of mind-body therapy that seeks to make positive physical changes in the body by repeatedly visualizing the desired effect.

Herbal Therapy consists of using herbs with "medicinal properties" to modify the course of an illness.

Humor Therapies use humor/laughter to alleviate symptoms.

The illness taking the patient's life may cause physical pain, but it does not necessarily cause suffering.

continued

continued

Massage Therapy is the systematic manipulation of superficial or deep tissue, muscle, or connective tissue by applying pressure and movement. Such application may include stroking, kneading or stretching and can reduce stress and some forms of chronic pain.

Music/Sound Therapies uses musical interventions specifically selected by a music therapist to restore, maintain or improve an individual's social or emotional functioning and mental or physical health.

Reflexology Treatment uses hands to apply pressure to specific points and zones on the feet, which are thought to relate to specific body parts and organs, to reduce pain and tension.

Reiki is a therapy that channels healing energies from the hands of the practitioner to the patient to promote relaxation and reduce stress.

Therapeutic Touch is a treatment based on the belief that illness is caused by a deficiency or imbalance of body energies. The therapist moves his/her hands just above your body to remove blockages from your energy field.

Warnings:

- Alternative therapies should be considered as an adjunct to standard health care practice-not as a replacement.
- Consult your physician before using an alternative therapy. Do not attempt to self-treat.
- Use accredited practitioners.
- Learn all you can about the benefits and dangers of alternative medicine. Just because something is "natural" does not mean it is safe. (*"The PDR Family Guide to Natural Medicines & Healing Therapies," produced by the Physicians' Desk Reference is an example of a comprehensive guide to the benefits and dangers of alternative medicine.*)

The Process of Dying

Dying is a profoundly personal journey. Many who were facing death described it as a time for:

- Deepening and/or healing relationships with others.
- Deepening relationships with the divine.
- Finding meaning in life, suffering and death.
- Integrating life experiences.
- Personal growth.
- Letting go.

When an Individual Begins to Die

When a person begins to die, much of what the dying person and those around them suffers stems from their fear of death. This fear is felt by both the dying person and those around them. The dying person reminds people that they, too, are going to die, which most people are not eager to consider.

Losses

Although death results in a series of losses, those losses do not occur all at once. The dying individual experiences losses such as:

- Loss of control of events and dreams for the future,
- Loss of significant relationships,
- Loss of a sense of meaning, of independence and productivity, and
- Loss of various physical, intellectual and social abilities.

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Caregivers have a unique opportunity to give as much control as possible to the dying individual.

Emotional Responses

In addition to fear of loss, the individual's emotional responses to dying may include:

- Anxiety,
- Fear of what's to come,
- Fear of the unknown,
- Fear of being alone at the time of death, and
- Fear of pain and/or suffering.



The Stages of Dying

There are a number of responses to their impending death that a dying person may express. These include:

- An individual may initially deny the fact of death.
Denial is a natural reaction to circumstances we are not ready to deal with. While not actively encouraging such denial, it may be helpful to the individual in the beginning stages to continue in the denial until they are ready to face the reality. This requires tremendous patience on the part of family members and health care staff
- An individual may be angry.
"My family just wants me out of the way. " "Nobody cares about me." "Why me?" These phrases are common ways that individuals express feelings of anger before they have accepted the reality of death. It is helpful to the individual to allow them to express feelings of doubt and fear.
- An individual may try to bargain with God.
This is most often done in private. There may be an attempt to bargain with God for more time, or less pain, or a chance to see to the well-being of family members.
- An individual may experience depression.
"It's going to be hard on my family." "I'll never see my children again." These are common concerns for an individual who is dying. It is all right to remain silent in the face of such sadness and let the grief be expressed. It is important to allow an individual who is dying to talk about their life experiences, especially if there are regrets. This gives the individual a chance to talk about ways to set things right.

There are a number of responses to their impending death that a dying person may express.

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An individual will eventually accept the reality of death.

Be patient with the individual until they are ready to accept the reality of letting go, so that death can be faced with dignity. Be quietly present. Do not demand conversation. Do not feel rejected if your loved one seems detached.

An individual may be afraid of dying.

This is a normal feeling and is not an abandonment of one's faith, traditions, or belief system. It is important to allow the individual to express their fear.

As independence
and physical
abilities diminish,
dependence and
the need for
assistance
become a part of
everyday life.

The Dying Person's Rights

As independence and physical abilities diminish, dependence and the need for assistance become a part of everyday life. At this time, it is our responsibility to maintain the dying person's rights to respect, dignity, compassion, and honesty. This is well-expressed in "The Dying Person's Bill of Rights."

The Dying Person's Bill of Rights

By Amelia T. Barbus

- I have the right** to be treated as a living human being until I die.*
- I have the right** to maintain a sense of hopefulness however changing its focus may be.*
- I have the right** to be cared for by those who can maintain a sense of hopefulness, however changing this may be.*
- I have the right** to express my feelings and emotions about my approaching death in my own way*
- I have the right** to participate in decisions concerning my care.*
- I have the right** to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.*
- I have the right** to not die alone.*
- I have the right** to be free from pain.*
- I have the right** to have my questions answered honestly.*
- I have the right** not to be deceived.*
- I have the right** to have help from and for my family in accepting my death.*
- I have the right** to die in peace and dignity.*
- I have the right** to retain my individuality and not to be judged for my decisions which may be contrary to beliefs of others.*
- I have the right** to discuss and enlarge my religious and/or spiritual experience, whatever these may mean to others.*
- I have the right** to expect that the sanctity of the human body will be respected after death.*
- I have the right** to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.*

Caregiver's To-Do List

Address the individual's need:

- For control of pain,
- For affection and love,
- For preservation of dignity,
- For prayer and/or religious sacraments.

Engage the dying person by:

- Listening to what they want,
- Asking open-ended questions,
- Touching or holding them lovingly, and speaking gently letting them know they are loved, they are safe, and they have nothing to fear, and by
- Not being afraid to say "good-bye."

Remember:

- It's natural to feel anxious about saying good-bye,
- The dying person is often as concerned about the family as the family is concerned about the dying person,
- Pastoral Care staff can facilitate communication between family members and the dying person.

"The Five Senses of Loss" From the Wishard Health Services End of Life Care Team and Community Guidance Council offers further advice to caregivers.

The Five Senses of Loss

A Message to the Loved Ones

You have received the news from your loved one's doctor that he or she is probably facing death in the relatively near future. You have talked with and received this booklet from your minister or another professional concerned about your loved one and you. These pages are intended only as an aid for you as you seek to understand and support the one who may be dying. It is our hope that these general descriptions of a body's changes as death approaches will bring you some additional comfort as you and Wishard Caregivers "walk with your loved one to the door of death."

Everyone approaches death in his or her own way and each approach is special. Know that whatever approach your loved one takes is okay and normal.

Your loved one still has lots left to do - whether it is settling personal affairs or having final communication with family and friends. When this unfinished business has been taken care of, your loved one may be ready to "let go," and that is okay.

Vision

When a loved one is dying, vision is often the first sense to be lost. A person's vision can be greatly reduced due to tears clouding their eyes, discomfort, inability to tolerate a lot of light, being in a poor position to see others while lying in bed, not wearing glasses during illness, or inability to focus their eyes because of medications and pain killers taken.

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If vision is a priority for your loved one, you can do the following:

- Keep glaring light out of your loved one's eyes.
- Make visits short to let your loved one's eyes rest.
- Give the person permission to close their eyes.
- Stand or sit in a place where your loved one can easily see you.
- If your loved one wears glasses, offer the glasses to your loved one.

Taste

The sense of taste often leaves quickly. However, it can be a delightful way of showing you love and care for someone ...

- A loved one who knows you in a way associated with food.
- Remembrance of a meal shared. Talk about the event.
- A memory involving baking together.

If okayed with your nurse, see if your loved one might enjoy a piece of food-very small evoking a memory ... candy, juice, a drop of a favorite beverage, a pudding, or any other special food.

Try to keep the taste one which your loved one is used to and has enjoyed in the past.

- Allow regular times for mouth care.
- Taste changes over time.
- Often during illness, many things do not taste good. Many times, memories of different taste bring much more pleasure than the food itself.

Smell

Smell is one of the senses that stays longest and is often highly sensitive to the very end of life.

Many times, smells will evoke very strong memories in all of our lives. Smell can be used as a very positive nonverbal means of communication with a loved one who is perhaps unable to speak or hear. Remember, scents should be very light.

Some light scents your loved one may enjoy are potpourri, fresh flowers, scented candles/air fresheners, special fragrance such as apple pie or peach cobbler.

Try not to mix smells as this may be too strong for a dying person.

Try this scenario: Tell your loved one who you are. Present the smell which your loved one would connect with you, like roses. Talk softly to the person about a memory involving the two of you and the roses.

Hearing

Hearing is known to be the sense that stays with a dying person the longest.

Long after the other senses have left a patient, hearing will remain and be quite sensitive (*unless the patient has been deaf or severely hearing impaired before the moment of death.*)

Things to remember:

- Make sure the patient is wearing a hearing device in bed if they usually wear one. The patient may refuse to wear it, and that's o.k.
- If one ear hears better than the other, speak into the "good" ear.
- Speak clearly in a distinct tone.

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At the end of a person's life, hearing is often the only connection a person has in this world. Even if your loved one does not respond to you, keep talking to him or her because he or she can probably still hear you. What you say in comfort to your loved one will not only help that person to die in peace, but will help you to finally accept your loved one's death.

Touch

Touch is a lasting sense that is often the greatest need to be filled. It can range from an encompassing embrace to gently holding your loved one's hand.

Gentle touching of a person's skin, face, arms, and hands can show support, love, caring and being present to your loved one at that moment.

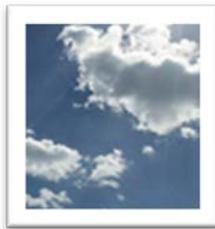
Lightly blotting a loved one's face, neck and shoulders with cool water can be refreshing and greatly appreciated by a dying person.

Do not be offended if your loved one rejects your touch, however.

Sometimes any kind of stimulus can be painful or irritating to a dying person.

Gently experiment with touch and your loved one. Tell the person what you want to do as you do it. . . and watch carefully for a response. "Honey, I'm going to touch your face now."

Sometimes just touching one finger of a dying person is all that can be tolerated, accepted or received from you. Move gently with love.



Preparing To Let Go

In the early stages of the dying process, as one prepares to let go of a loved one, there are some issues that typically need to be addressed by the dying individual (*if they are able to*), the family and the health care staff:

- How to ask for what one needs.
- Assessing the individual's pain and its management.
- Understanding and addressing the individual's and family members' psychological, social and spiritual needs.
- Gaining information about treatment options at this time such as palliative or hospice care.
- Managing the individual's wishes, such as advance directives.
- Knowing what signs and symptoms to expect when death is near.
- Deciding what family members want and need at the moment of death.
- Family rituals at time of death.
- Funeral arrangements.

Understanding and addressing the individual's and family member's psychological, social and spiritual needs.

The Changes That Take Place During the Dying and Death Process

What You Can Expect

As the time of death draws near, anxiety levels can reach their peak and the anticipation of the unknown prompts many questions. In an attempt to answer some of these questions, Karon Adams, author of *As the Time of Death Draws Near*, presents the following information about the signs which precede death in most people at her website, *Kay's Place*. She notes that for some these signs appear a few hours before death; for others, a few days. There is no particular order in which they occur, and a person may not experience all of them. It is hoped that by knowing what to expect you will be less fearful as you provide support and care. She also provides suggestions for promoting comfort as these signs occur.

- There will be less interest in eating and drinking. For many patients, refusal of food is an indication that they are ready to die. Fluid intake may be limited to that which will keep their mouth from feeling too dry
WHAT YOU CAN DO: Offer, but do not force, food, liquids, and medications. Pain, which has required medication to control in the past, may no longer be a problem.
- Urinary output may decrease in amount and frequency.
WHAT YOU CAN DO: Nothing, unless the patient expresses a desire to urinate and cannot. Call the hospice nurse for advice.
- As the body weakens, the patient will sleep more and begin to detach himself from his environment. The caregiver's attempts to make them more comfortable may be refused.
WHAT YOU CAN DO: Let him/her sleep. At this point, "being with" is more important than "doing for."

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- Mental confusion may become apparent, as less oxygen is available to supply the brain. The patient may be disturbed by "strange" dreams.
WHAT YOU CAN DO: As he awakens from periods of sleep, remind him of the day and time, where he is, and who is present. This is best done in a casual, conversational way.
- Vision and hearing may be somewhat impaired, and speech may be difficult to understand.
WHAT YOU CAN DO: Speak clearly, but no more loudly than necessary. Keep the room as light as the patient wishes, even at night. Carry on all conversations as if they can be heard, since hearing is the last of the senses to cease functioning. Many patients are able to talk until minutes before death and are reassured by the exchange of a few words with a loved one.
- Secretions may collect in the back of the throat and rattle or gurgle as the patient breathes through his mouth. He may try to cough up mucous. His mouth may become dry and encrusted with secretions.
WHAT YOU CAN DO: If the patient is trying to cough up secretions and is experiencing choking or vomiting, humidification of the air with a cool mist vaporizer may help. Otherwise, call your hospice nurse for help.
- Secretions may drain from the mouth if the patient is placed on his side and supported with pillows.
WHAT YOU CAN DO: Cleansing the mouth with swabs dipped in glycerin or mineral oil or even cool water will help to relieve the dryness that occurs with mouth breathing. Offer water in small amounts to keep the mouth moist. A straw with one finger over the end can be used to transfer sips of water to the patient's mouth.

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- Breathing may become irregular with periods of no breathing, or apnea, lasting around 20 to 30 seconds. The patient may seem to be working very hard to breathe and may make a moaning sound with each breath. As the time of death nears, breathing may again become regular but shallower and more mechanical in nature.

WHAT YOU CAN DO: Raise the head of the bed if the patient breathes more easily this way. The moaning is not necessarily indicative of pain or distress, but often is only the sound of air passing over very relaxed vocal cords.

- As the oxygen supply to the brain decreases, the patient may become restless. It is not unusual for patients to pull at bed linens, to have visual hallucinations, or even try to get out of bed at this point.

WHAT YOU CAN DO: Reassure the patient in a calm voice that you are there. Prevent him from falling if he tries to get out of bed. Soft music or a back rub may help quiet them.

The patient may feel hot one minute and cold the next as the body loses its ability to control its temperature ... provide and remove blankets as needed.

- The patient may feel hot one minute and cold the next as the body loses its ability to control its temperature. As circulation slows down, the arms and legs will become cool and may be bluish in color. The underside of the body may darken. It may be impossible to feel a pulse at the wrist.

WHAT YOU CAN DO: Provide and remove blankets (not electric) as needed. Sponge patient with cool washcloth if this promotes comfort. Change perspiration-soaked garments and bed linens if the patient wishes.

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- Loss of control of bladder and bowel functions may occur around the time of death.

WHAT YOU CAN YOU DO: Protect the mattress with a plastic sheet. Keep chux or waterproof padding under the patient, and change as needed to keep the patient comfortable.

- At the time of death breathing ceases heartbeat ceases. The patient cannot be aroused. The eyelids may be partially open with the eyes in a fixed stare. The mouth may fall open slightly as the jaw relaxes. Any waste matter in the bladder or rectum will be released as the sphincter muscles relax.

WHAT YOU CAN DO: There is nothing you have to do. You do not have to call for a nurse, if you are in a health care setting, or contact anyone if you are at home. You can just be with the person. When you are ready, you can contact a nurse or your loved one's physician or dial 911. You may also want to call a member of the clergy.

When Death is Pronounced

When your loved one is pronounced dead you can contact the funeral parlor to pick up the body. They will then begin the process of filing a death certificate and preparing the body for burial or cremation. The funeral director can help you with planning the service, writing the obituary and filing for any benefits to which you may be entitled.



Grieving and Healing

The Grieving Process

One is never quite prepared for the death of a loved one. For the survivors, it is a painful and sometimes devastating experience. All people who suffer the loss of someone near to them sooner or later go through a grieving process. It is a difficult, lengthy and necessary process. It allows you to accept the loss, say good bye and move on with your life. Grief does not just begin at the time of death; nor is grief an experience of the loved ones only. Dying individuals and family members most likely will start grieving before death occurs.

The intensity of the grief is not necessarily related to the degree of love felt for the individual who has died; rather, it is related to the nature of the relationship, the age at which death occurred, whether the death was painful and traumatic, or peaceful and timely.

Grief can be frightening because it can be so painful and seem so overwhelming. Many worry about whether or not they are grieving in the "right" way, and wonder if the feelings and experiences they have are normal. These worries are usually a positive sign because they indicate that the person is going through the grieving process rather than trying to deny their feelings. Feelings that are denied can reappear later and create long-lasting psychological difficulties.

Responses to Grief

During the process everyone moves through different stages within the process-not necessarily in any given order. You may experience a few or many of the reactions to grief. The following are all natural and normal grief responses:

- Strong emotions that come in waves,
- Feeling tightness in the throat or heaviness in the chest,
- Having an empty feeling in their stomach and losing their appetite,

- Feeling restless and looking for activity, but finding it hard to concentrate,
- Feeling as though the loss isn't real, that it didn't actually happen,
- Sensing the loved one's presence, like finding themselves expecting the person to walk in the door at the usual time, hearing their voice, or seeing their face,
- Feelings of numbness and disbelief,
- Yearning,
- Isolation and withdrawal,
- Wandering aimlessly and forgetting to finish the things they've started to do,
- Having difficulty sleeping and frequently dreaming of their loved one,
- Experiencing an intense preoccupation with the life of the deceased,
- Feeling guilty or angry over things that happened or didn't happen in the relationship with the deceased,
- Feeling intensely angry at the loved one for leaving them or at God for allowing it to happen,
- Crying at unexpected times,
- Feeling their mood change over the slightest things,
- Feel in pain, and
- Needing to tell and retell and remember things about the loved one and the experience of their death.

Continued

Resolution and Recovery

Resolving grief is hard work that takes time. The amount of time is different for each person, but it usually takes at least a year to feel oneself again. By acknowledging the death and that the relationship is now over, and by experiencing and dealing with all of the emotions and problems this loss creates, you will reach a stage of:

- Acceptance of the death.
- Acceptance of the changes in one's life.
- Realization that life will not be the same.
- Realization that one can take charge of one's life.
- Replacement of sad feelings with fond memories of the loved one.

Signs of Healing

As one journeys through the grief process, signs of healing will begin to occur a little at a time.

- You begin to focus on others.
- You can live with your emotions.
- You are able to laugh and enjoy yourself.
- You can talk about your loved one without getting a lump in your throat.
- You can share your feelings without becoming overwhelmed by them.
- You can take pride in your accomplishments and ability to take care of yourself.
- You find meaning in your life once again, a sense of purpose in your work and in relationships.
- You begin setting new goals.
- You start planning for the future.
- You are doing what is normal, natural and necessary – you are adjusting to life without your loved one.

Some of the factors influencing the grief reaction

The experiences of grief and the grieving process vary greatly from person to person. Things which influence this are:

- Length of the relationship,
- Quality of the relationship,
- Timeliness of the death,
- How the person died,
- Degree of ambivalence or unfinished business in the relationship,
- Reactions to previous losses,
- Personality/coping abilities,
- Ability to express emotions/accept help,
- Strength of the family system,
- Presence of family; cultural, religious beliefs and practices,
- General health/lifestyle, and
- Ability to redefine one's life and identity without the loved one.

Suggestions

These are some specific activities which may help with the grieving process:

- Express your feelings in a journal,
- Write a letter to the person who has died and share your feelings or use this as an opportunity to say anything that was left unsaid,
- Talk about your loss with friends and let them know when you need their support,
- Distract yourself by engaging in activities such as work, reading, hobbies, music or sports,
- Nurture yourself, and
- Expect to be upset on the anniversary of your loved one's death as well as on other special days (e.g. birthdays and holidays such as Christmas or Hanukkah.)

Healing Is About Creating New Memories

Sometimes it may seem like a betrayal to stop mourning. But healing does not mean forgetting – it means creating new memories. In *Light from Many Lamps*, Helen Keller wrote:

"We bereaved are not alone. We belong to the largest company in all the world - the company of those who have known suffering. When it seems that our sorrow is too great to be borne, let us think of the great family of heavy-hearted into which our grief has given us entrance, and inevitably, we will feel about us their arms, their sympathy, their understanding.

Believe, when you are most unhappy, that there is something for you to do in the world. So long as you can sweeten another's pain, life is not in vain ...

Robbed of joy, of courage, of the very desire to live, the newly bereaved frequently avoids companionship, feeling herself so limp with misery and so empty of vitality that she is ill suited for human contact. And yet no one is so bereaved, so miserable, that she cannot find someone else to succor, someone who needs friendship, understanding, and courage more than she. The unselfish effort to bring cheer to others will be the beginning of a happier life for ourselves.

Often when the heart is torn with sorrow, spiritually we wander like a traveler lost in a deep wood. We grow frightened, lose all sense of direction, batter ourselves against trees and rocks in our attempt to find a path. All the while there is a path - a path of Faith - that leads straight out of the tangle of our difficulties into the open road we are seeking."

Resources and Support Systems

There are many organizations and health care professionals that can provide information and support for individuals making end-of-life decisions. Some of these organizations hold disease-related meetings and support groups in hospitals and long term care facilities. Additionally, a number of churches and synagogues sponsor grief and bereavement support groups.

The following list provides a beginning for seeking information:

Organizations

- Alzheimer's Association
1-800-272-3900
- The American Association of Retired Persons (AARP)
1-800-424-3410
- American Diabetes Association
1-800-DIABETES (1-800-342-2383)
- American Heart Association
1-800-AHA-USA1 (1-800-242-8721)
- Association for Death Education and Counseling
1-847-509-0403
- The Cancer Information Service
1-800-422-6237
- Catholic Charities USA
1-703-549-1390

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- The Catholic Health Association of the United States
1-314-427-2500
- Choice in Dying
1-800-989-9455
- The Hospice Association of America
1-202-546-4759
- Long Term Care Ombudsman Program
(Administration on Aging [AoA],
U.S. Dept. of Health and Human Services)
Eldercare Locator: 1-800-677-1116
AoA Information: 1-202-619-0724
- Meals on Wheels
(Check white pages for local listings)
- National Anatomical Service
1-800-727-0700
- National Association of Area Agencies on Aging (NAAA)
1-800-677-1116
- National Hospice and Palliative Care Organization Helpline
1-800-658-8898
- State Agencies on Aging (To find your State Agency contact:
Administration on Aging [AoA],
U.S. Dept. of Health and Human Services)
1-800-677-1116

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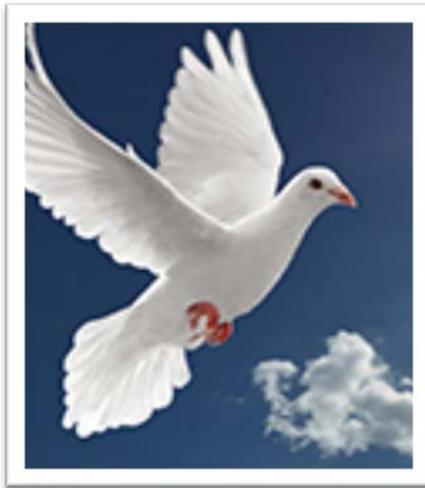
- Supportive Care of the Dying
1-503-215-5053

- Visiting Nurse Associations of America (VNAA)
1-800-426-2547

- The Wellness Community
1-888-793-WELL (1-888-793-9355)

- The Well Spouse Foundation
1-800-838-0879

This list represents the most current organizations and their telephone numbers as of the printing date of this publication.



Health Care Professionals

In the institutional setting of a hospital or long-term care facility, health care professionals are trained to support the dying individual and their family.

Social Services can assist in areas such as:

- Insurance benefits information,
- Advance directives,
- Hospice care,
- Financial needs,
- Support groups,
- Private duty nursing, and
- Concerns regarding treatment

Pastoral Care can offer the following help:

- Spiritual and emotional support,
- Religious activities,
- Grief and bereavement support,
- Aid health care team members in making some of the more difficult decisions,
- Ethics consultation, and
- Ways to "be with" the individual who is dying.

Nursing staff can help with:

- Pain management,
- Understanding medical problems,
- Communicating with the patient's doctor, and
- Coordinating medical services.

Bibliography

- AARP. *A Matter of Choice: Planning Ahead for Health Care Decisions*. Washington: AARP
- Adams, Karon L. "As the Time of Death Draws Near." kcabell@emanon.net.
- Bozarth, Alia Renee, Ph.D. *Dance For Me When I Die: Death As A Rite of Passage* Minneapolis: Hazelden Information Education, 1994.
- Bozarth, Alla Renee, Ph.D. *A Journey Through Grief: Gentle, Specific Help To Get You Through the Most Difficult Stages of Grieving*. Minneapolis: CompCare Publishers, 1990.
- Bozarth, Alla Renee, Ph.D. *Life is Goodbye, Life is Hello: Grieving Well Through All Kinds of Loss*. Minneapolis: CompCare Publishers, 1982.
- Crawford, Ronald. *Ethical Dilemmas In Foregoing Medical Treatment* (College of Chaplains)
- Davidson, Glen. *Living With Dying; A Guide For Relatives and Friends*. (rev. ed.) Minneapolis: Augsburg, 1990.
- Feinstein, David and Peg May *Rituals For Living and Dying; How we Can Turn Loss and the Fear of Death into an Affirmation of Life*. San Francisco: Harper & Row, 1990
- Floyd, Maita. *Platitudes: You Are Not Me*. Phoenix: Eskuldun Publishers, 1991.
- Gross, Amy, ed. "The Modern Maturity Guide to End-of-Life Care." *Modern Maturity*, September-October, 2000.
- Hope for Bereaved: Understanding, Coping and Growing Through Grief*. Syracuse: Hope for Bereaved. 1988.
- Johnson, Richard. *Aging Parents*. Liguori Publications, 1987.
- Kubler-Ross, Elisabeth. *On Death and Dying*. New York: Macmillan, 1969.

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Kubler-Ross, Elisabeth. *Death: The Final State of Growth*. Englewood Cliffs: Prentice-Hall, 1975.

Linn, Mary Jane, et. al., *Healing The Dying*. New York: Paulist Press, 1979. Morris, Virginia. *How to Care for Aging Parents*. New York: Workman Publishing, 1996.

Rando, Therese. *Grief Dying and Death; Clinical Interventions for Caregivers*. Champaign: Research Press, 1984.

Sims, Darcie. *Why Are the Casseroles Always Tuna? A Loving Look At The Lighter Side of Grief*. Carmel: Bereavement, 1990.

"*The Five Senses of Loss*" Design-Eileen Javurek, R.N. , B.A. Concept & Creation-Denise Saxman, C.C.S.W, Stephanie Ott, Pat Darden, Jim Greene, Ph.D., Marcia Gray, R.N. , M.S., Greg Gramelspacher, M.D., Margaret Gaffney, M.D., Ann Zerr, M.D., James Nash, R.N. Support & Guidance – Wishard Health Services' End-of-Life Care Team and Wishard Health Services' End-of-Life Community Guidance Council.

Appendix

Roman Catholic Teachings on "End-of-Life" Issues

Roman Catholic Teachings on "End-of-Life" Issues

The following information is derived from The Ethical and Religious Directives for Catholic Health Care Services* approved by the National Conference of Catholic Bishops in November 1994.

The purpose of these *Ethical and Religious Directives* then is two-fold: first, to reaffirm the ethical standards of behavior in health care that flow from the Church's teaching about the dignity of the human person; second, to provide authoritative guidance on certain moral issues that face Catholic health care today.

Christ's redemption and saving grace embrace the whole person, especially in his or her illness, suffering and death.³⁵ The Catholic health care ministry faces the reality of death with the confidence of faith. In the face of death - for many, a time when hope seems lost - the Church witnesses to her belief that God has created each person for eternal life.³⁶

A Catholic health care institution will be a community of respect, love, and support to patients or individuals and their families as they face the reality of death.

Above all, as a witness to its faith, a Catholic health care institution will be a community of respect, love, and support to patients or individuals and their families as they face the reality of death. What is hardest to face is the process of dying itself, especially the dependency; the helplessness, and the pain that so often accompany terminal illness. One of the primary purposes of medicine in caring for the dying is the

³⁵*Pope John Paul II, Apostolic Letter; On the Christian Meaning of Human Suffering (Salvifici Doloris) (Washington, D.C.: United States Catholic Conference Publishing Services, 1984), nos. 25-27.*

³⁶*National Conference of Catholic Bishops, Order of Christian Funerals (Collegeville, Minn.: The Liturgical Press, 1989), no. 1.*

relief of pain and the suffering caused by it. Effective management of pain in all its forms is critical in the appropriate care of the dying.

Preserving Life

The truth that life is a precious gift from God has profound implications for the question of stewardship over human life. We are not the owners of our lives and, hence, do not have absolute power over life. We have a duty to preserve our life and to use it for the glory of God; but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome. Suicide and euthanasia are never morally acceptable options.

Care or Cure

The task of medicine is to care even when it cannot cure. Physicians and their patients must evaluate the use of the technology at their disposal. Reflection on the innate dignity of human life in all its dimensions and on the purpose of medical care is indispensable for formulating a true moral judgment about the use of technology to maintain life. The use of life-sustaining technology is judged in light of the Christian meaning of life, suffering, and death. Only in this way are two extremes avoided: on the one hand, an insistence on useless or burdensome technology even when a patient may legitimately wish to forgo it and, on the other hand, the withdrawal of technology with the intention of causing death.³⁷

The task of medicine is to care even when it cannot cure.

Some state Catholic conferences, individual bishops, and the NCCB Committee on Pro-Life Activities have addressed the moral issues concerning medically assisted hydration and nutrition. The bishops are guided by the Church's teaching forbidding euthanasia,

which is " ... an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated."

³⁷*Declaration on Euthanasia.*

continued

continued

These statements agree that hydration and nutrition are not morally obligatory either when they bring no comfort to a person who is imminently dying or when they cannot be assimilated by a person's body. The NCCB Committee on Pro-Life Activities report, in addition, points out the necessary distinctions between questions already resolved by the magisterium and those requiring further reflection, as, for example, the morality of withdrawing medically assisted hydration and nutrition from a person who is in the condition which is recognized by physicians as the "persistent vegetative state."³⁸



³⁸*Committee for Pro-Life Activities, National Conference of Catholic Bishops, Nutrition and Hydration: Moral and Pastoral Reflections (Washington, D.C.) United States Catholic Conference Publishing Services, 1992). On the importance of consulting authoritative teaching in the formation of conscience and in taking moral decisions, see Veritatis Splendor; nos. 63-64.*

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Discussion Guide

Discussion Guide

This section is included for discussing ways to implement the suggestions and principles provided in the End-of-Life handbook. The guide is in outline form and can be used by an instructor to conduct training or informational programs for health care providers or groups. It can also be helpful for supporting someone who is in the process of dying and their family or loved ones.

The sections can be used together in a single session or each can be done by itself depending on the issues to be covered and the needs of the participants.

It should be noted that the suggested topics and questions are meant to be starting points for discussion. Because many people are uncomfortable talking about end-of-life issues, questions can help break the ice and lead to open discussion and exchange of ideas.

Section I

Physical, Emotional, Social and Spiritual End-of-Life Issues

To adequately and respectfully address the end-of-life, it is essential that everyone involved understand and agree on the issues and how they are to be handled. This means a frank and open discussion of physical, emotional, social and spiritual needs and how they relate to each other.

A key to successfully managing these issues is to ask about and discuss the fears and needs of the dying person. Only by expressing and understanding their concerns can both the dying person and their caregivers overcome the discomfort of talking about death. This session should work on ways to expose and address the fears and needs of the dying person.

Topics to be covered may include:

- How can the fears and needs of the dying person be identified and addressed?
- What words can be used to talk about death?
- What specifically is to be done to maintain life and at what levels should there be interventions?
- What physical needs for comfort, pain relief, and integrative/ alternative medicine will there be and how will they be handled?
- What is the "ABCDE" approach to pain and is it being observed?
- Has the issue of withdrawal of life support been discussed with the dying person and their family and is there agreement?
- Who will be the dying person's spiritual counselor and have spiritual themes been included with care?
- How can the dying person's religious beliefs and spirituality help them and their family cope with the death?
- How can caregivers avoid forcing their spiritual or religious beliefs on the person in need?
- How can the dying person be assured that their needs and wishes will be met and that they will be treated respectfully and with compassion?
- How to let the dying person know that they no longer need to worry about unfinished business and those they are leaving behind?
- What social activities might the dying person still want to do and how could those be accomplished?
- How will mental suffering be addressed (compared to physical pain?)
- How can caregivers and family assist someone who is extremely frightened, anxious, depressed or who feels their death is a punishment?

Section II

Medical Care Options and Decisions

About Types of Care

The purpose of this session is to identify and understand the treatment options to be considered and the decisions which need to be made during the dying process and how to insure choices are correctly expressed and that they are properly carried out.

These are difficult topics to discuss and many misconceptions and fears exist about levels of care and advance directives. Asking questions and learning the facts will help participants make informed and medically wise decisions.

Topics to be covered would include:

Medical Options

Levels and types of care.

- Life Prolonging: CPR, mechanical ventilator (respirator), artificial nutrition and hydration (tube feedings), kidney dialysis, antibiotic
- drugs, blood transfusions, and surgery.
- Comfort Care: Palliative and Hospice care, including patient rights for pain medication and comfort therapies.
- What specifically is to be done to maintain life and at what points should there be intervention?

These are difficult topics to discuss and many misconceptions and fears exist about levels of care and advance directives.

- Has the issue of withdrawal of life prolonging treatments been discussed with the dying person and their family and is there agreement?

Advanced Directives

- Living Will (discuss example)
- Durable Power of Attorney (discuss example)

Cover distinctions and requirements for each and how to make sure they are binding and enforced by medical and health care staffs.

Situations when the dying can no longer speak for themselves

- When family members can/cannot change directives.

Discussion might also include questions such as:

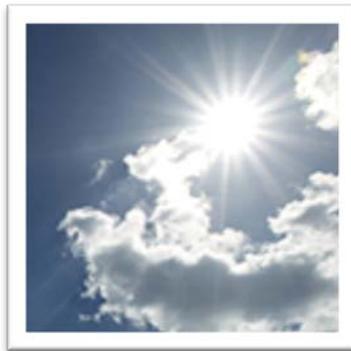
- Why does it make sense to have both a Living Will and a Durable Power of Attorney?
- How can the dying insure their wishes are adhered to over the objections of their family?
- Can the dying change their mind and amend their Living Will and/or Durable Power of Attorney?
- What questions should be asked before making advance planning decisions?
- What are the eight things to do for advance care planning?
- What pain medications are available and what are the consequences of their use? Should addiction be an issue?
- Are there other alternative therapies which may be useful in relief of pain and suffering and in increasing comfort and mental well-being?

Section III

The Process of Dying and Meeting the Needs of the Dying Person and Their Family

Dying is a process and it is important for caregivers to understand what is going to happen and how to prepare themselves and the dying person for the process as well as for death itself. Topics to be covered in this area might include:

- Have the stages of dying, the five senses of loss, and the changes that take place during the dying and death process been discussed and does everyone understand what will be going on?
- Do caregivers and others involved know what they should be doing, and have they thought about their "Caregiver's To-Do List?"
- Have loved ones considered their response to the death and how that might affect the person who is dying?



Section IV

Grief and Achieving Healing

Regardless of how expected the death is, survivors experience grief. Much like dying, grief is a process which should be investigated and understood so that loved ones can move beyond the death to healing. The process, however, is different for each person and often outside counselors can hasten a successful passage from grief to healing. The outcome of a discussion of grief might be an understanding of how one might feel as the grief ebbs and is replaced by new memories of the person who died.

Questions to be discussed might include:

- What is grief and how do people react to it; how is grief expressed?
- What factors influence the grief reaction?
- How long does it typically take to resolve grief?
- What are the stages of recovery from grief?
- What are the signs of healing?
- What tactics might help with the grieving process?



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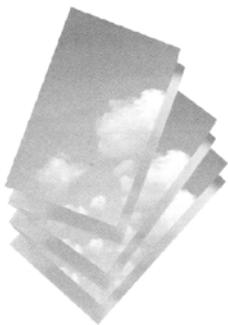
ALEXIAN
BROTHERS
Health System



Health System

THE POWER TO DO GOOD

For more than eight hundred years, the Alexian Brothers have cared for the sick, the aged, the poor and the dying. The basic Judeo-Christian beliefs that inspired the founders of this Catholic religious congregation sustain its ministry today. This heritage is espoused by the governance, management and entire health care team throughout Alexian Brothers Health System in their mutual commitment to promote the physical, mental, spiritual and social well-being of all individuals served through the health care ministry.



Durable Power of Attorney for Health Care and Health Care Directive



ALEXIAN
BROTHERS
Health System

Part I. Durable Power of Attorney for Health Care

- If you do **NOT** wish to name an agent to make health care decisions for you, write your initials in the box to the right and got to Part II.

Initials

This form has been prepared to comply with the "Durable Power of Attorney for Health Care Act" of Missouri.

1. Selection of Agent. I appoint:

Name: _____

Address: _____

Telephone: _____

It is suggested that only one Agent be named. However, if more than one Agent is named, any one may act individually unless you specify otherwise.

as my Agent.

- ### 2. Alternate Agents. Only an Agent named by me may act under this Durable Power of Attorney. If my Agent resigns or is not able or available to make health care decisions for me, or if an Agent named by me is divorced from me or is my spouse and legally separated from me, I appoint the person(s) named below (in the order named if more than one):

First Alternate Agent

Name: _____

Address: _____

Telephone: _____

Second Alternate Agent

Name: _____

Address: _____

Telephone: _____

- ### 3. Effective Date and Durability. This Durable Power of Attorney is effective when **two** physicians decide and certify that I am incapacitated and unable to make and communicate a health care decision.

- If you want **ONE** physician, instead of **TWO**, to decide whether you are incapacitated, write your initials in the box to the right.

Initials

4. Agent's Powers. I grant to my Agent full authority to:

A. Give consent to, prohibit or withdraw any type of health care, medical care, treatment or procedure, even if my death may result.

- If you wish to **AUTHORIZE** your Agent to direct a health care provider to withhold or withdraw artificially supplied nutrition and hydration (including tube feeding of food and water), write your initials in the box to the right.

Initials

THIS IS A DURABLE POWER OF ATTORNEY, AND THE AUTHORITY OF MY AGENT, WHEN EFFECTIVE, SHALL NOT TERMINATE OR BE VOID OR VOIDABLE IF I AM OR BECOME DISABLED OR INCAPACITATED OR IN THE EVENT OF LATER UNCERTAINTY AS TO WHETHER I AM DEAD OR ALIVE.

Part I. Durable Power of Attorney for Health Care (Continued)

- If you **DO NOT WISH TO AUTHORIZE** your Agent to direct a health care provider to withhold or withdraw artificially supplied nutrition and hydration, (including tube feeding of food and water), write your initials in the box to the right.

_____ Initials

B. Make all necessary arrangements for health care services on my behalf, and to hire and fire medical personnel responsible for my care;

C. Move me into or out of any health care facility (even if against medical advice) to obtain compliance with the decisions of my Agent; and

D. Take any other action necessary to do what I authorize here, including (but not limited to) granting any waiver or release from liability required by any health care provider, and taking any legal action at the expense of my estate to enforce this Durable Power of Attorney.

5. Agent's Financial Liability and Compensation. My Agent acting under this Durable Power of Attorney will incur no personal financial liability. My Agent shall not be entitled to compensation for services performed under this Durable Power of Attorney, but my Agent shall be entitled to reimbursement for all reasonable expenses incurred as a result of carrying out any provision hereof.

Part II. Health Care Directive

- If you **DO NOT WISH** to make a health care directive, write your initials in the box to the right, and go to Part III.

_____ Initials

I make this HEALTH CARE DIRECTIVE ("Directive") to exercise my right to determine the course of my health care and to provide clear and convincing proof of my wishes and instructions about my treatment.

If I am persistently unconscious or there is no reasonable expectation of my recovery from a seriously incapacitating or terminal illness or condition, I direct that all of the life-prolonging procedures that I have initialled below be withheld or withdrawn.

I want the following life-prolonging procedures to be withheld or withdrawn:

- **artificially supplied nutrition and hydration (including tube feeding of food and water)**

Initials

- **surgery or other invasive procedures**

Initials

- **heart-lung resuscitation (CPR)**

Initials

- **antibiotic**

Initials

- **dialysis**

Initials

- **mechanical ventilator (respirator)**

Initials

- **chemotherapy**

Initials

- **radiation therapy**

Initials

- **all other "life-prolonging" medical or surgical procedures that are merely intended to keep me alive without reasonable hope of improving my condition or curing my illness or injury**

Initials

_____ Initials

(continued on back)

**Part II. Health Care Directive
(Continued)**

However, if my physician believes that any life-prolonging procedure may lead to a significant recovery, I direct my physician to try the treatment for a reasonable period of time. If it does not improve my condition, I direct the treatment be withdrawn even if it shortens my life. I also direct that I be given medical treatment to relieve pain or to provide comfort, even if such treatment might shorten my life, suppress my appetite or my breathing, or be habit-forming.

IF I HAVE NOT DESIGNATED AN AGENT IN THE DURABLE POWER OF ATTORNEY, THIS DOCUMENT IS MEANT TO BE IN FULL FORCE AND EFFECT AS MY HEALTH CARE DIRECTIVE.

**Part III. General Provisions included in the Directive
and Durable Power of Attorney (Continued)**

YOU MUST SIGN THIS DOCUMENT IN THE PRESENCE OF TWO WITNESSES.

IN WITNESS WHEREOF, I have executed this document this _____ day of _____ (month), _____ (year).

Signature

Print Name _____

Address _____

The person who signed this document is of sound mind and voluntarily signed this document in our presence. Each of the undersigned witnesses is at least eighteen years of age.

Signature _____

Print Name _____

Address _____

Signature _____

Print Name _____

Address _____

ONLY REQUIRED FOR PART I — DURABLE POWER OF ATTORNEY

STATE OF MISSOURI)
) SS
COUNTY OF _____)

On this _____ day of _____ (month), _____ (year), before me personally appeared _____, to me known to be the person described in and who executed the foregoing instrument and acknowledged that he/she executed the same as his/her free act and deed.

IN WITNESS WHEREOF, I have hereunto set my hand and affixed my official seal in the County of _____, State of Missouri, the day and year first above written.

Notary Public

My Commission Expires: