

ADVANCE CARE PLANNING



Making Choices
Known

THE COMPLETE LIFE SERIES

Advance Care Planning: Making Choices Known is the first in a series of five booklets on end-of-life planning and care. The booklets in the Complete Life series are:

Booklet 1 - Advance Care Planning: Making Choices Known. *A workbook to document the kind of care you want if you are unable to make decisions for yourself. Includes web addresses to find your state's forms.*

Booklet 2 - Planning Ahead: Funeral and Memorial Services. *A workbook to document your funeral or memorial service preferences ahead of time. Includes tips for consumers.*

Booklet 3 - Preparing to Say Good-bye: Care for the Dying. *Learn about common symptoms experienced by dying people and what you can do to make the dying person more comfortable.*

Booklet 4 - When Death Occurs: What to Do When a Loved One Dies. *A guide to help you get through the hours, days, and weeks following a loved one's death.*

Booklet 5 - Help for the Bereaved: The Healing Journey. *Learn about the common expressions of grief, the healing process, and when to get help.*

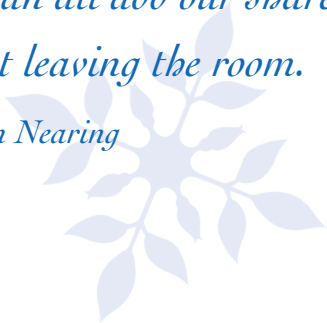
All five booklets can be downloaded from
www.hawaii.edu/aging

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*Everyone can love in the place
where they are. We can all add our share
of love without leaving the room.*

—Helen Nearing



ADVANCE CARE PLANNING

We like to think that we will always be healthy and able to make decisions for ourselves. But if you develop a sudden illness or serious condition or are involved in an accident, you might not be able to make decisions for yourself.

Making your wishes known while you are still healthy is a good idea. Sharing your healthcare decisions with others is the best way to make sure they are respected.

Your family and loved ones will benefit from your advance planning. Knowing your wishes will help ease their burden and reduce their uncertainty if they ever have to make medical decisions on your behalf.

In this booklet, you will learn about the types of decisions you can make ahead of time and how to let others know what you want.

*Plans are useless,
but planning is invaluable.*

—Winston Churchill



YOUR ADVANCE DIRECTIVE FOR HEALTH CARE

An advance directive is a written or spoken statement about your future medical care. The advance directive lets your doctor, family, and others know how you want to be treated if you are unable to tell them. The two main types of advance directives are the "Living Will" and the "Power of Attorney for Health Care."

Planning in advance for health care decisions is the best way to make sure your voice is heard and your wishes are respected.

In your advance directive you may share your wishes about:

- The kind of medical treatment you want or don't want
 - The person you want to make health care decisions for you when you can not
 - What you wish to have for comfort care (care that focuses on reducing pain and suffering when a cure is no longer possible)
 - Ethical, religious, and spiritual instructions
 - Anything else about your health care preferences that you want your loved ones and your health care providers to know
-

BENEFITS OF ADVANCE DIRECTIVES



They Help People Know What to Do. Your written advance directive is a gift to your family and friends. By documenting your wishes, others won't have to guess what you want if you can no longer speak for yourself. If your family has to guess, they may disagree and argue. That makes it hard for the doctor to honor your wishes. An advance directive is the best way to make sure that your wishes are carried out. Even if you currently have a living will, new laws enacted in your state may be more comprehensive and may give you more choices.



Health Care Decisions Will Not Be Left to Chance. You make choices every day about your work, your home, and your life. Why leave health care decisions to chance? Now is the time to decide about the kind of care you want. Now is the time to share your thoughts.



They Let Others Know Your Values. Advanced technology makes it possible for patients with little or no hope of recovery to be kept alive for months or even years. This makes it even more important for you to think and talk about what kind of care you would want if you were unable to make your own decisions.



TALKING ABOUT IT



Talking Now Is a Gift You Give to Those Close to You.

In the event you become so ill that you can no longer speak for yourself, advance planning will help those close to you make the decisions you would want. Surviving family members of people who died without advance directives tell us that they struggled over their decisions and always wondered if they did the right thing.

Destiny is not a matter or chance, it is a matter of choice. It is not a thing to be waited for, it is a thing to be achieved.

—William Jennings Bryan



Use an Example of Someone You Know. Many people, including some doctors, are uncomfortable talking about care at the end of life. You can start the discussion by talking about someone else's experience. For example, you could ask:

- Do you remember when our neighbor was in the hospital before she died? What did you think about the treatment she received?

Then describe what you would want if you were ever in this condition. Or ask your family members what they would want. Enlist the help of your family or loved ones in making sure that, if this happens to you, they will respect your wishes. It also is important to discuss your concerns and wishes with your doctor.



Getting Help. Sometimes you may need the help of a friend, counselor, social worker, or clergy person to start talking with your family about the end of life. There are people from all walks of life and religious groups who have the experience to help.

Let your heart find a voice.

Celebrate life with those you love.

UNDERSTANDING LIFE-SUSTAINING TREATMENTS

The following are examples of some of the common medical treatments used to extend or sustain life in terminal conditions. It is good to become familiar with them, as you may be asked to consider them for yourself or a loved one.

Always discuss the risks and benefits of all surgeries and other medical treatment decisions with your doctor.



Nutrition (Food) and Hydration (Fluids).

Advance directives commonly include instructions to carry out or to stop life-sustaining treatments such as artificial nutrition (food) and hydration (fluids). People in a terminal condition will generally receive artificial nutrition and hydration, unless they have stated their wishes against this means of prolonging life.

Forcing food when a person is dying and not hungry can increase pain, cause the person to choke (aspirate), and worsen the condition. Forcing fluids may also aggravate the situation. Even intravenous feeding (IVs) at this time can cause complications, such as swelling and congestive heart failure.



Blood Transfusion. This includes whole blood or blood products. Some people do not want whole blood, but will accept plasma. There comes a point at which blood transfusions no longer improve the quality of the terminally ill person's life.



Surgery. Before a surgery is considered, you should understand the risks and benefits of the surgery. Will it provide comfort and relieve suffering, or merely extend life? In terminal conditions, some surgical procedures are performed to reduce pain and increase comfort and are not meant to be curative. Are there other, less invasive procedures that can increase comfort and reduce pain?



Cardiopulmonary Resuscitation (CPR).

Normally, when someone suffers a heart attack, also known as a cardiac arrest, a “code” is called and cardiopulmonary resuscitation (CPR) is initiated. An attempt is made to “jump-start” the heart with an electrical impulse, and manual compressions are applied to the chest in an effort to restore the heart to its normal rhythm. In specific medical crises, CPR can help to save a person's life. However, in persons with terminal or life-limiting illnesses, CPR is rarely helpful. In a hospital or health care facility, unless there is a written order NOT to resuscitate, CPR will be given. If cardiac arrest occurs and 911 is called, CPR will always be initiated unless the person is terminally ill and wearing a "comfort care only" bracelet or necklace ordered by a doctor. Comfort Care bracelets or necklaces, however, may not be available in all states. Those who receive CPR are often put on mechanical ventilators, or breathing machines.



Mechanical Ventilation. When people can no longer breathe on their own and wish to have their lives prolonged, they are “vented” or placed on mechanical ventilators. These are machines that breathe for them, forcing air into the lungs.

In emergency situations, such as cardiac arrest, mechanical ventilation is common. Persons who are “brain dead” can no longer breathe on their own, and they can be kept physically alive only through mechanical ventilation. Once it has begun, withdrawing mechanical ventilation is usually a difficult decision for family members, as they may feel responsible for the death. Be assured that the dying process that began before mechanical ventilation is now being allowed to take its natural course.



Antibiotics. Antibiotics have become a cornerstone of modern medicine. They are commonly given to treat many different infections. However, the use of antibiotics should be carefully considered in terminal conditions. For example, pneumonia used to be called “the old person’s friend.” Today, it can be effectively treated. But if a person is close to death, is the use of antibiotics the best thing to do? For persons nearing the end of life, symptoms of an infection may be effectively managed without the use of antibiotics.

DOCUMENTING YOUR WISHES

Think about the kind of care you would want (or not want) if you were seriously ill, and talk about it with your loved ones and your health care provider.

Even though oral (spoken) instructions regarding your health care are considered legal, it is best to write down your wishes in an advance directive.

In the U.S., every state has a law about how advance directives can be completed. These laws also require doctors and health care facilities to honor advance directives.

Advance directive forms often are available from your health care provider or local legal aid society. Advance directive forms are also available on the Internet.

State-specific forms may be downloaded from **www.partnershipforcaring.org** (1-800-989-9455).



Most advance directives allow you to document your answers to these questions:

1. What kind of care do I want if I can no longer make decisions for myself and I have little or no chance of recovery?

You can specify whether or not you want your life prolonged indefinitely, if you want to be fed through tubes if you can not feed yourself, and if you want treatment for pain. This information can be documented on a "living will," also called a health care directive.

A. CHOICE TO PROLONG OR NOT TO PROLONG LIFE

___ YES, I do want to have my life prolonged as long as possible within the limits of generally accepted health care standards that apply to my condition.

OR

___ NO, I do not want my life prolonged.

B. ARTIFICIAL NUTRITION AND HYDRATION

(FOOD AND FLUIDS) BY TUBE INTO STOMACH OR VEIN

___ YES, I do want artificial nutrition and hydration.

OR

___ NO, I do not want artificial nutrition and hydration.

C. RELIEF FROM PAIN

___ YES, I do want treatment to relieve my pain or discomfort, even if it hastens my death.

OR

___ NO, I do not want treatment to relieve my pain or discomfort.

2. Who will make decisions for me if I can't make them for myself?

You can specify someone as your "agent" to make health care decisions for you if you are unable. This type of directive is called a "Power of Attorney for Health Care" in most states. Your agent can be your spouse, an adult child, a friend, or any other trusted person but can not be an employee of a health care facility where you are receiving care (unless related to you by blood or marriage).

People who could serve as my agent are:

| | |
|-------|--------------|
| _____ | _____ |
| Name | Relationship |

| | |
|-------|--------------|
| _____ | _____ |
| Name | Relationship |

| | |
|-------|--------------|
| _____ | _____ |
| Name | Relationship |

3. Do I want to donate my organs or tissues after my death?

Anyone over the age of 18 can become an organ and tissue donor. Those under 18 years of age need parental consent. Donor cards and additional information may be obtained from www.organdonor.gov/ or by calling 1-800-DONORS-1.

Most states allow you to indicate on your driver's license if you are an organ donor. Some states also allow you to indicate your decision in your advance directive. Find out more at www.donatelife.net.

SAMPLE FAMILY NOTIFICATION CARD

I would like to become an organ and tissue donor.
I want you to know my decision now because you will be consulted before donation can take place.

I wish to donate the following:

_____ Any needed organs and tissues

_____ Only the following organs and tissues:

Signature: _____

4. Do I want to donate my body to medical science?

Some states allow you to donate your body to medical science. For rules about body donation in your state, visit www.med.ufl.edu/anatbd/usprograms.html

5. Does my advance directive need to be notarized?

Your state may require that your advance directive be witnessed or notarized. The witnesses can not be the same people listed as your agent(s). One of them can not be related to you by blood, marriage, or adoption.

People who could witness my advance directive are:

| Name | Relationship |
|------|--------------|
|------|--------------|

| Name | Relationship |
|------|--------------|
|------|--------------|

Once you have completed your advance directive, give copies to your family members, your doctor, and your clergy person or temple leader. Bring a copy with you if you are hospitalized. Do not leave copies in a safe deposit box where they will be found too late to do any good.

People I will give my advance directive to are:

Family members: _____

Physician: _____

Lawyer: _____

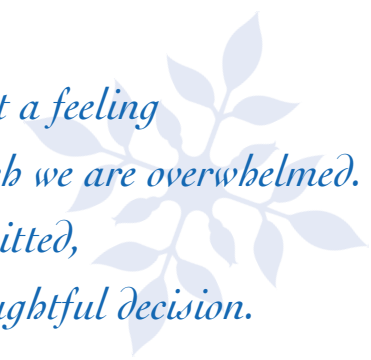
Church/Temple: _____

CHECKLIST

- ❑ **Talk with your spouse, adult children, family, friends, spiritual advisors, and doctors** about the type of care that is important to you.
- ❑ **Ask someone you trust to be your health care agent.** Discuss your wishes with this person.
- ❑ **Complete an advance directive.** State-specific advance directive documents and instructions may be downloaded free of charge by visiting www.partnershipforcaring.org/. A printed set of documents may be ordered for \$10.00 by calling 1-800-989-9455.
- ❑ **Finalize your advance directive.** You must comply with your state's witness and signature requirements. All states require you to date your advance directive. All states require that your signature be witnessed by at least one adult not related by blood, marriage, or adoption. Some states require two witnesses. Advance directives may also be notarized. Most states give you the right to revoke or change your advance directive at any time, orally or in writing.
- ❑ **Tell your family, friends, and doctors that you have an advance directive.** Keep them informed about your current wishes.

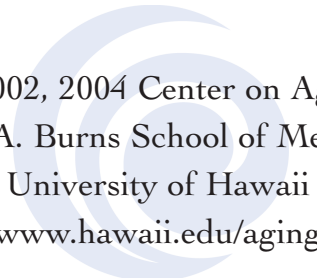
- ❑ **Give copies of the advance directive** to your doctors to put in your medical record. Also, give copies to your family, close friends, spiritual advisors, and other individuals who might be involved in your care.
- ❑ **Review your advance directive regularly.**
It is a good idea to review your advance directive each year, as your situation may change. When you update your advance directive, the old one is no longer valid. Let people know if you change your wishes. Make sure your doctor puts the new document in your medical record.
- ❑ **Keep a copy in an easy-to-find place in your home.**
Do not put it in a safe deposit box. Let others know where it is.
- ❑ **Carry your organ donor card, or indicate on your driver's license that you are an organ donor.**
Donor cards may be obtained by visiting www.organdonor.gov or by calling 1-800-DONORS-1.
- ❑ **If you wish to donate your body to medical science,** tell your family and fill out the necessary documents ahead of time.

Booklets in the Complete Life series were developed under grant #90-CG-2548 from the National Family Caregiver Support Program, U.S. Administration on Aging.



*True love is not a feeling
by which we are overwhelmed.
It is a committed,
thoughtful decision.*

—M. Scott Peck



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John A. Burns School of Medicine
University of Hawaii
www.hawaii.edu/aging

PLANNING AHEAD



Funeral and Memorial Services

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*And we must extinguish the candle,
put out the light and relight it;*

*Forever must quench,
forever relight the flame.*

—T. S. Eliot





PLANNING AHEAD

Death will come to all of us. Learning about options for funerals, memorials, and burial makes sense. Which plans should you make now?

- Do you want to be buried or cremated?
- Which kind of service do you want?
- Should you buy a funeral plan?

Making plans ahead of time will help reduce the stress on surviving family members and loved ones when death occurs. It is helpful for them to know in advance if you want a funeral service, a memorial service, or no service. Because costs vary, deciding ahead of time can save money as well as time.

Ask your clergy person or spiritual leader for help in planning the service. Some faiths have traditional ways of treating the dead. Others are more flexible and allow for more personal choice. Ask which areas of the funeral or memorial service allow for personal expression.


Planning your funeral or memorial service with care and mindfulness is a gift you share with those you love. This booklet will help you make and document decisions for the events following your death.



*The best and most beautiful things
in the world cannot be seen or touched,
but are felt in the heart.*


— Helen Keller

FUNERALS AND MEMORIALS

 **Funeral Service.** A funeral is a formal service based on religious or cultural traditions. The body is present in most cases, and there may be a viewing. Because the body is present, funerals generally take place within a few days of death, before cremation or burial. A funeral can take place at home, at the graveside, in a church or temple, or at a funeral home or mortuary. Of these options, the funeral home or mortuary is likely to be the most expensive.

*Today is a good day to die,
for all of the things of my life are here.*

—Chief Crazy Horse

 **Memorial Service.** A memorial service is held without the body, so it can be scheduled days, weeks, or even months after the death occurs, allowing time for family and friends to gather together. A memorial service can be as elaborate or simple as you choose, and may be held anywhere -- at home, in a park, at the work site, at the graveside, in a church or temple, or at a funeral home or mortuary. Sometimes, family members and loved ones choose to hold memorial services simultaneously in different parts of the country. For more information about burial, cremation, funerals, and memorial services, visit www.funerals.org or call 1-800-765-0107.

BURIAL AND CREMATION



Earth Burial. Earth burial is the practice of placing human remains in the ground. Most people are buried in cemeteries, although some states allow earth burial on residential property. Bodies are usually placed in a casket prior to burial, which can cost anywhere from a few hundred dollars to tens of thousands of dollars. The dead can be buried fully clothed or not, and personal items may be placed in the casket as well. In addition to a casket, most cemeteries also require a grave liner to prevent the ground from shifting and becoming uneven over the years. Many cemeteries allow family and friends to hold ceremonies at the graveside prior to burial.



Cremation. Cremation is a process that uses intense heat to reduce the body to bone fragments. These are usually crushed or ground so that the ashes can be scattered. It takes two to four hours to cremate a body, and the cremated remains (sometimes called cremains) weigh four to eight pounds. Cremains may be stored in a box or urn at home, placed in a columbarium, buried in the earth, or scattered. Most crematories require that the body be cremated in a container. Federal law requires that all funeral homes offer an inexpensive cremation container for this purpose, however, you can choose to be cremated in an expensive casket. The crematory must be told if the body has a pacemaker or other metal implant so they can remove it prior to cremation.

WHAT CAN YOU EXPECT FROM A MORTUARY OR FUNERAL HOME?

Mortuaries and funeral homes are in the business of caring for bodies after death. They may offer some or all of these services:

- Picking up the body from the home, hospital, or nursing home
- Preparing the body for viewing
- Hosting and arranging the funeral or memorial service
- Filing the death certificate
- Sending the obituary to the newspaper
- Burying or cremating the body

Most U.S. states allow you to handle all these arrangements yourself without the help of a funeral director.



SHOULD YOU BUY A FUNERAL PLAN?

Funerals can be expensive. You can save money by knowing your choices and your rights. This section will help you to understand the importance of planning ahead financially, the benefits and dangers of prepaying for your funeral, and where to find assistance.

It is easy to get confused with all of the different terms surrounding prepayment: prepay, preneed, and pre-plan. There are no set definitions for each of these terms, but generally preplanning is stating your wishes in writing or verbally, without prepaying for those arrangements.



What is Preplanning? Preplanning simply means planning ahead. People should always plan ahead and consider ways to cover the expense of a funeral. Preplanning saves your family from the stress of making choices in a time of grief. It also allows you to compare prices and to make informed choices about the goods and services you desire.



Should I Prepay? Prepaying means setting aside funds now for a funeral in the future.

There are several ways to set aside funds. Some people buy a funeral plan years in advance of death. There are advantages and drawbacks to this. If you choose to prepay, be sure that you understand the contract before signing.



What is Preneed? Preneed is a special type of prepayment. It is a term used by the funeral industry to describe plans and trusts that are sold to consumers by funeral homes, cemeteries, and insurance agents.

You should be cautious about paying for your funeral in advance. What if the funeral home goes out of business before your death? What if you change your mind about your plans? Any of these situations may cause you to lose some or all of your money. Make certain you understand any contract you are signing.



How Much Will It Cost? Prices vary depending on the services and products (like the casket or burial urn) you want. The federal “Funeral Rule” requires funeral directors to show you a current price list of their goods and services if you ask. They also must disclose prices by telephone. As with any major purchase, shop around for the best prices. Buy only what you want and need.

Even with prepaid funeral plans, families may be surprised to learn of additional expenses that are not covered. Vault liners (outer burial containers), cemetery maintenance fees, and police escort services, for example, can be among the “hidden” extra costs. There also are separate fees for opening and closing a grave, crypt, or niche. There may also be additional fees for services rendered on weekends or after-hours. In addition, general sales tax is levied on all products and services at the time of death, to be paid by the estate.

Veterans are eligible for burial benefits in any of the 120 national Veterans cemeteries. These include a headstone or marker, a vault liner, opening and closing of the grave or niche, and perpetual care. Veterans are also eligible for a free marker if buried in cemeteries other than national Veterans cemeteries, but there is usually a fee for setting the marker. For more information, visit www.va.gov or call 1-800-827-1000.



Where Can I Get Help? Planning for your funeral in advance and comparing prices is one of the wisest things you can ever do. Visit www.funerals.org or call 1-800-765-0107 to learn about the options in your state and to get help with planning ahead. If you wish to file a complaint against a funeral home or mortuary, contact the Federal Trade Commission at 1-877-FTC-HELP.

PLANNING YOUR SERVICE

You may use the form that starts on the next page to plan your funeral or memorial service. Share your plans with your family. Do not rely on putting your plans in your will, as the will may not be read until after other arrangements are made for you.

If plans are not made and shared ahead of time, the burden falls on the surviving family members and loved ones. Stating your wishes in advance helps ease the burden on loved ones during a time of grief and loss.

FINAL ARRANGEMENTS

Use this sheet to provide vital information and state your wishes.

I. PERSONAL INFORMATION

Name: _____

Date of Birth: _____

Place of Birth: _____

Husband/Wife: _____

Children: _____

Grandchildren: _____

Other Significant Persons: _____

II. THE SERVICE

A. Type of Service

☐ Funeral ☐ Memorial ☐ No Service

☐ Other _____

B. Location of Service

☐ Church or Temple _____

☐ Mortuary or Funeral Home _____

☐ Other _____

C. Location of Reception (if different from above)

☐ Church or Temple _____

☐ Mortuary or Funeral Home _____

☐ Other _____

D. People who can give the eulogy

1. _____

2. _____

E. Music I would like played or sung

List the hymns, chants, or songs you would like to have sung at your service. Name any soloists, singers, or musicians that you would like to have perform.

1. _____
2. _____
3. _____
4. _____

F. Readings

List your favorite scriptures, sutras, sacred readings, poems, etc. Write down who you would like to have offer each reading.

1. _____
2. _____
3. _____
4. _____
5. _____

G. Arrangement of the altar

Flowers (Which kind?)

Photograph (Which one? Where is it located?)

Religious image (Which?)

Other

H. Flowers and monetary donations

☐ Guests may bring flowers or wreaths.

☐ No additional flowers or wreaths, please.

☐ I would like monetary donations to go to:

1.

2.

3.

III. BURIAL INSTRUCTIONS

A. Viewing of the body at the service

☐ Viewing ☐ No Viewing

Where should the viewing be held?

Which clothes would you like to wear?

What personal items, if any, would you like placed in your casket?

B. Burial or Cremation

☐ Burial (If you own a plot, where are the papers?)

☐ Cremation

Where should your ashes be preserved or scattered?

What personal items, if any, would you like cremated with you?

☐ Body donation (If arranged, where are the papers?)

☐ I have pre-arranged my funeral and burial

☐ Yes (with which mortuary?) _____

☐ Location of paperwork: _____

☐ No

When this information is needed, who do you want
to be in charge?

Name _____

Phone _____

IV. OTHER INSTRUCTIONS OR INFORMATION



V. PEOPLE TO CONTACT WHEN I DIE

List family members, friends, minister, lawyer, accountant, and others. Add other pages as needed.

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____

Name/relationship_____

Phone/e-mail_____




TIPS FOR CONSUMERS


- Plan ahead. Document your wishes in this booklet, and inform a trusted person where you have placed it.
- Talk about funerals with your family, and share your wishes with them.
- Price shop by phone or in person.
- Remember that simple caskets are adequate for burial or cremation, and that cremation is less expensive than burial.
- Remember that holding a service without the body can give you more time to plan and be less expensive than holding a service with the body.
- Handle all arrangements without a funeral director, or choose a funeral director that will honor your plans.
- If you prepay for a burial plot or a funeral plan, make sure you understand the contract before you sign.
- Join a Funeral Consumers Alliance in your state. This group can help you understand your options and help you to make wise choices. Visit the national organization at **www.funerals.org** or call 1-800-765-0107.

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but planning is invaluable.*



—Winston Churchill



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PREPARING TO SAY GOOD-BYE



Care for the Dying



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*At heart, hospitality is
a helping across a threshold.*

—Ivan Illich



CARE FOR THE DYING

Many physical changes occur during the process of dying that affect the emotional, social, and spiritual aspects of a person's life. There are some signs and symptoms of dying that are observable, although not everyone follows a predictable sequence of events or stages.

Sometimes, the last stages of life can be very stressful for the dying person and those caring for him or her. You may observe changes that are unfamiliar to you. You may have concerns and questions. Learning about the dying process will help.

Health professionals speak of "dying trajectories" that suggest how persons with specific diseases will die. For example, those with a terminal illness, such as advanced cancer, will show a steady decline toward death. Those with serious chronic illnesses, however, may have peaks and valleys that sometimes give the impression of recovery. Remember that each person's dying process is unique.

In this booklet, you will learn about the common symptoms experienced in people who are dying. You may observe none, some, or all of these symptoms in the dying person's last days and hours on earth. You will also learn to anticipate and manage the changes that may occur to help promote the comfort of your loved one.



Work of sight is done.

*Now do heart work
on the pictures within you.*

—Rainer Maria Rilke

QUESTIONS TO ASK YOUR DOCTOR

Like most people, doctors may be hesitant to talk about the inevitability of death. Should your loved one become seriously ill, here are some useful questions to ask the doctor.

1. How long do others in this condition live?
2. Are there any treatments that will make him or her well again?
3. Are there any treatments that will help him or her to live longer?
4. What are the benefits and the burdens of the recommended treatment options?
5. Tell me about hospice and palliative care. Are either of these appropriate at this time?
6. What is meant by Comfort Care Only?

HOSPICE AND PALLIATIVE CARE



What is Hospice Care? Hospice is a philosophy of care that focuses on improving the quality of life for individuals with life-limiting illness. Hospice care can be provided in the home, hospital or nursing home setting. In the U.S., insurance currently only pays for hospice services if the doctor certifies that the person is expected to live for six months or less. Hospice services are covered by Medicare, Medicaid, private insurance with hospice benefits, and/or private pay.



What is Palliative Care? Like hospice care, palliative care can be provided in the home, hospital, or nursing home. Unlike hospice, however, palliative care can be provided to persons with a life expectancy beyond six months, and persons may still continue to pursue curative treatment for their condition.

Hospice and palliative care utilize a team approach to improve the quality of life by controlling pain and other symptoms, as well as providing emotional, social, and spiritual support for patients and their families.

Achieving the best possible quality of life is a cornerstone of both hospice and palliative care. For more information, visit www.nhpco.org and www.hospice.net/.



What is Comfort Care? Many states have a “Comfort Care - Do Not Resuscitate” (CC/DNR or CCO/DNR) program. When death is the expected outcome of a serious or life-limiting illness and a person does not want to be resuscitated, a CC/DNR bracelet may be ordered through a doctor. When worn, this alerts emergency first-responder personnel to provide comfort measures only should the heart or breathing stop. Ask your doctor more about this option in your state.

COMMON SYMPTOMS AND WHAT YOU CAN DO



Loss of Appetite. As death nears, a person may lose interest in food and drink. The ability to swallow becomes impaired. Loss of appetite and reduced intake are normal parts of dying.

In the early stages of dying, the person may prefer only soft foods and liquids. In the very last stages of life, however, he or she may not want any food or drink. The person may want to suck on ice chips or take a small amount of liquid to wet and freshen the mouth, which can become very dry.

In the last stages of dying, forcing food when the body says “no” may be harmful or painful to the person. Many dying persons will exhibit the clenched jaw sign as a way of saying “no.” Forcing fluid may cause choking, or the person may draw liquid into the lungs, making matters worse.

It is hard for most people to respect the person’s lack of appetite. That’s because many of us equate food with caring. Family members may feel that withholding nutrition is cruel or neglectful. They may worry that they are “killing” their loved one.

*For the raindrop,
joy is entering the river.*

—Galib



Remember that your loved one is dying from his or her disease, not from starvation. As the physical body dies, the vital organs shut down and nourishment is no longer required to keep them functioning. This is the wisdom of dying, and the body knows exactly what to do.

What you can do:

- Talk to the doctor or nurse about the advantages of reducing food and fluid in the last stages of dying.
- Refrain from giving liquids or food unless requested.
- Wet the lips and mouth with a small amount of water, ice chips, or a sponge-tipped applicator dipped in water.
- Protect lips from dryness with a protective lip balm.
- Consider removing dentures and bridges, as they may become loose.
- Continue to be a caring and loving presence.





Change in Bowel and Bladder Functions. The two major concerns are constipation and incontinence (loss of control over bowel and bladder functions).

Constipation may be caused by lack of mobility, pain medication, and decreased fluid intake. If left untreated, fecal impaction may occur and can become uncomfortable. Laxatives generally are needed to keep the bowels moving, particularly if the dying person is still eating or receiving nutritional supplements. Regulating bowel movements may be difficult at first, and the dying person may alternate between constipation and diarrhea.

Incontinence is likely to be distressing to the dying person and those in attendance. In the early stages, accidents can occur. Urine may be sparse, highly concentrated, and may look tea-colored. Sometimes a urinary catheter is inserted, or the dying person may wear diapers or briefs. This will help keep the bedding clean. Keep in mind that changing the bedding may be more disturbing to the dying person than the catheter or the diapers. As death nears, the muscles in these areas relax further and contents are released. This is normal.

What you can do:

- Watch for signs of constipation and incontinence, and help loved ones report this to the doctor or nurse.
- Keep affected areas clean and dry. After cleansing, apply a protective barrier cream to prevent skin rashes and bedsores.



Withdrawal from the External World. As the end of life approaches, there is a feeling of detachment from the physical world and a loss of interest in things formerly found pleasurable. There is a tendency to sleep more. There is less desire to talk. This is the beginning of letting go of life and preparing for death.

Days or hours before death, the dying person becomes less and less responsive to voice and touch and may not awaken. Sometimes, quite unexpectedly, the person may appear well and even look as if he or she is going to recover. The person may be alert and talkative. This is temporary and does not mean that there will be recovery; the person is still dying. Use this as an opportunity to say what you need to say and have closure.

What you can do:

- Always speak gently, and identify yourself before speaking. Hearing is normally preserved throughout the dying process.
- Use gentle touch, and provide reassurance. The dying person can feel your touch up until the end.
- Let relatives and close friends know what is happening.
- Dying requires energy and focus. Try not to distract the dying person from this necessary preparation.
- Allow time for silence. Remember that you are supporting the person to “let go.”



Visions and Hallucinations. Visual or auditory hallucinations often are part of the dying experience. The appearance of family members or loved ones who have died is common. These visions are considered normal. The dying may turn their focus to “another world” and talk to people or see things that others do not see. This can be unsettling, and loved ones may not know how to respond.

What you can do:

- Do not judge what is happening. Just be as supportive as possible. Or be silent.
- Refrain from discounting the experience and orienting the person to “reality.” Most often, these visions are reassuring, and they comfort the person.
- It is important to differentiate visions from hallucinations or bad dreams that may be caused by medications or metabolic changes. Visions of loved ones generally are comforting, but bad dreams may frighten the dying person. Alert the doctor or nurse about bad dreams. An adjustment in medication may correct this.

*Now, I have no choice but to see with your eyes,
so I am not alone, so you are not alone.*

—Yannis Ritsos



Confusion, Restlessness, and Agitation.

Restlessness and agitation are common. You may see the person "reaching out" with arms extended. You may also see picking, pulling, and fidgeting behaviors. These symptoms may be caused by reduced oxygen to the brain, metabolic changes, dehydration, pain medications, or a combination of these. "Terminal delirium" is a condition that may occur when the person is very close to death, and is marked by extreme restlessness and agitation. Although it may look distressing, the delirium is not considered to be painful. Medications are available to control symptoms.

What you can do:

- Never startle the dying with bright lights, harsh tones, or abrupt movement.
- Always identify yourself. Even if the dying person knows you well, he or she might not recognize you at this time.
- Use a gentle voice and reassuring touch.
- With mindful awareness, be sensitive to any cues that might signal that there is something the person wants to resolve before he or she can let go. Offer support.
- Consider the use of light massage and soothing music.
- If the dying person is agitated, ask the doctor if medications might help to reduce the agitation. Emotional and spiritual interventions may also be helpful at this time.



Changes in Breathing, Congestion in Lungs or

Throat. You may observe that breathing is shallow and quickened, or slow and labored. As death nears, the person may make gurgling sounds, sometimes referred to as the “death rattle.” These sounds are due to the pooling of secretions and an inability to cough them up. The air passing through the mucus causes this sound.

The breathing pattern most disturbing to witnesses is marked by periods of no breathing at all (typically 10-45 seconds), followed by deeper and more frequent respirations. These respirations, known as Cheyne-Stokes breathing, are common in dying persons and result from a decreased oxygen supply to the vital organs and a build-up of waste products in the body. This irregular breathing pattern is not uncomfortable or distressing to the dying person, although it may be unsettling to observe. The “death rattle” and very irregular breathing indicate that death is near.

What you can do:

- Do not panic. This can increase any fear that may already be present for the dying person.
- Raise the head of the bed (mechanically or with pillows) to aid breathing.
- If secretions are pooling in the mouth, turn the head and position the body so that gravity can drain them. Deep suctioning rarely helps and is not recommended.
- If appropriate, wipe out the mouth with a soft, moist cloth to cleanse excess secretions.
- Using a fan to circulate air may make your loved one more comfortable.

- Speak lovingly, and use gentle reassuring touch to ease fear.
- Alert the doctor or nurse of increased chest congestion, if breathing is especially labored, or if you notice the “death rattle” or very irregular breathing.



Change in Skin Temperature and Color.

As the body dies, the blood moves away from the extremities toward the vital organs. You may notice that while the extremities are cool, the abdomen is warm. You may notice changes in body temperature. The dying person may feel hot one minute and cold the next. As death approaches, there may be fever. You also may see purplish-bluish blotches and mottling on the legs, arms, or on the underside of the body where blood may be collecting. As death nears, the skin may appear yellowish or waxen in color.

What you can do:

- Try to keep the person as comfortable as possible.
- Be alert to signs (such as kicking off blankets) that the person is too hot. Use a damp, cool washcloth to ease the discomfort.
- Use a blanket to cover the person who feels cold. Don't use electric blankets or heating pads, as these may burn the skin.
- Alert the doctor or nurse if you notice changes in skin color. This may be a sign that death is near.

MANAGING PHYSICAL PAIN

Physical pain can be controlled. No one should die in pain when the means to alleviate it are available. All persons have the right to have their pain controlled.

Pain is real. Always believe a person who says he or she has pain. Remember that each person is an individual and that perceptions of pain differ.

Talking to the doctor. People should expect their doctors and nurses to ask these questions about pain:

- Do you have pain?
- Where is it? What does it feel like: dull, stabbing, throbbing, etc.?
- How intense is the pain? Please rate it on a scale from zero to 10, with zero being no pain and 10 being the worst pain imaginable.
- What makes the pain better or worse?

The answers to these questions will help the doctor prescribe the right medicine in the right amount. Make sure you and your loved one understand:

- What may be causing the pain
- The recommended treatment
- The possible side effects
- What to do if there are questions or concerns

For more information about pain, visit www.stoppain.org/.



TIPS FOR CAREGIVERS

You can be a caring presence throughout the dying process. Your presence for the dying person indicates your loving kindness, compassion, and your willingness to help.

Learn. Learn what you can about the dying person's illness and the dying process so that you can provide comfort and assurance. Do not hesitate to ask questions of the medical professionals involved in your loved one's care.

Realize your limitations. No one is perfect. No one can do everything. Take a break when you need one. Get help when you need it.

*True love is not a feeling
by which we are overwhelmed.
It is a committed, thoughtful decision.*

– M. Scott Peck

SAYING GOOD-BYE

People who are dying often want “permission” to die from those they love. They may need to be assured, quite literally, of five things:

- Things they were once responsible for will be taken care of
- The survivors will survive without them
- All is forgiven
- Their life had meaning
- They will be remembered

Saying good-bye is not easy. Yet, it is important for you and the dying person to do so. Take advantage of opportunities when the person is awake and communicative to facilitate the “saying good-bye” process.

If the dying person is not lucid or is in a coma, remember that hearing is the last sense to leave. Assume everything you say can be heard and understood, even if the person is not responsive. Never speak about the dying person as if he or she was not in the room.

Some people feel comfortable lying in bed next to their loved one as they say their parting words. Others may want to simply hold hands. If music, chanting, or prayer is used to assist the dying, let it be comforting and familiar, making way for gentle passage. The dying person’s body language will let you know if these sounds are welcome and soothing.



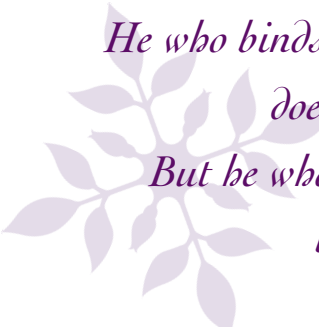
BEING PRESENT AT THE MOMENT OF DEATH

Even with all the preparation in the world, it is not comfortable watching someone you love die. Your decision to be present at the moment of death depends on many things. It is OK to choose to be present, and it is OK to be absent.

It is not uncommon, however, for the dying person to wait to die until loved ones have left the room. Make sure you allow for this, even if it is your wish to be present at death. Sometimes, if your loved one seems to be holding on, your kindest gesture may be to simply say, "I'm going to leave the room for awhile. I love you."

In some cultures, specific prayers, sutras, or other rituals, may ease the passage to death. These may be comforting to you as well as to the dying person. You may ask your clergy person for assistance.

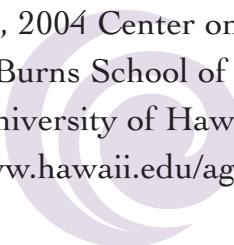
Booklets in the Complete Life series were developed under grant #90-CG-2548 from the National Family Caregiver Support Program, U.S. Administration on Aging.



*He who binds to himself a joy
does the winged life destroy.
But he who kisses the joy as it flies,
lives in eternity's sun rise.*

—William Blake

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www.hawaii.edu/aging



WHEN DEATH OCCURS



What to Do When a Loved One Dies

THE COMPLETE LIFE SERIES

What to Do When A Loved One Dies is the fourth in a series of five booklets on end-of-life planning and care. The booklets in the Complete Life series are:

Booklet 1 - Advance Care Planning: Making Choices Known. *A workbook to document the kind of care you want if you are unable to make decisions for yourself. Includes web addresses to find your state's forms.*

Booklet 2 - Planning Ahead: Funeral and Memorial Services. *A workbook to document your funeral or memorial service preferences ahead of time. Includes tips for consumers.*

Booklet 3 - Preparing to Say Good-bye: Care for the Dying. *Learn about common symptoms experienced by dying people and what you can do to make the dying person more comfortable.*

Booklet 4 - When Death Occurs: What to Do When a Loved One Dies. *A guide to help you get through the hours, days, and weeks following a loved one's death.*

Booklet 5 - Help for the Bereaved: The Healing Journey. *Learn about the common expressions of grief, the healing process, and when to get help.*

All five booklets can be downloaded from www.hawaii.edu/aging

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*Perpetual giving up
is the truth of this life.*

—Rabindranath Tagore



WHEN DEATH OCCURS

When a loved one dies, you may experience a wide range of emotions. You may experience sadness, confusion, loneliness, anger, anxiety, and perhaps even guilt or relief.

This is a time to honor family and cultural rituals. These rituals allow you to acknowledge the reality of the death and to begin the healing journey.

At the same time, you must complete a variety of tasks. You need to call family and friends. You need to arrange for the care of the body. You need to hold a funeral or memorial service. You need to alert various government agencies and businesses about the death, and settle the estate.

This booklet will help you get through the hours, days, and weeks immediately following the death of a loved one.

*Kind words can be short
and easy to speak, but their
echoes are truly endless.*

—Mother Teresa



SIGNS THAT DEATH HAS OCCURRED

Even when death is expected, it is often difficult to accept. These signs indicate that a person has died.

- No breathing
- No heartbeat or pulse
- Loss of control of bowel and bladder (the sheets or undergarments may be soiled)
- No response to touch or words
- The eyes remain fixed on a certain spot. The eyelids may be opened or closed.
- The jaw is relaxed and the mouth is slightly open. There may be a small amount of fluid or drainage from the nose or mouth.

Many people wonder when the body will become stiff or worry that it will begin to smell. The stiffening is called rigor mortis. This is a temporary condition that begins three to four hours after death and ends twenty-four to thirty-six hours after death. As far as odor is concerned, generally, after the body has been bathed, there should be minimal or no offensive odor.

If the eyes remain open at death, it is alright to close them, however, know that they may open again. It is okay to leave them open.

Families who want to keep an unembalmed body at home for a viewing or service may use dry ice to preserve it temporarily. To learn more, visit www.final-passages.org or call 1-707-824-0286.

WHO TO CALL FIRST



If death occurs in a hospital or nursing home and you are the first to be aware of the death, alert the nursing staff. The doctor will pronounce the death. The institution will need to know which mortuary or funeral home to call, and will perform that task for you.



If death occurs at home and is expected, call your doctor. This does not have to be done immediately, particularly if death occurs in the middle of the night. If you call 911, inform the operator that the death was expected. Unless the deceased is wearing a “comfort care only” bracelet or necklace, emergency medical personnel will most likely attempt resuscitation. If hospice is involved, the on-call nurse should be notified.



If the death was unattended and unexpected at home or elsewhere, call 911. The police and emergency medical personnel will determine the next appropriate steps. Under certain circumstances, the coroner will be contacted.



If the death occurs out of state and there is a pre-paid funeral plan, check the policy for travel protection benefits. If none exist, call the mortuary in the town where you want the deceased to be buried or cremated. They will help you to arrange transport of the body.

THE FIRST FEW HOURS

The mortuary does not need to be contacted immediately. This is a time to call your family members, friends, and clergy to be with the deceased.

Give yourself adequate time to experience what has just happened. You may want to hold or touch a loved one who has died and say your good-byes. Sharing stories with friends and family also can help to begin the grieving process.

This is the time to honor any family or cultural rituals. Some cultures have customs about bathing and clothing the body after death. Some cultures believe that the dead can carry messages to loved ones that have already died. Some cultures expect the dead to be buried with possessions that have meaning or would be useful in the next life.

Death rituals can help us in many ways:

- They help us to deal with our loss at a time of grief.
- They help us to release the person who has died.
- They allow us to reflect on the past, deal with the present, and look to the future.
- They help to bind us together with other mourners, allowing for a possibility to share common thoughts, memories, and feelings.



When you have said your goodbyes, it is time to surrender the body of your loved one to the mortuary, funeral home, or medical school. Your chosen mortuary or funeral home will send a vehicle to pick up the body. If you have chosen body donation, the medical school will arrange transportation. If death occurs in a hospital or nursing home, the body may be moved temporarily to the morgue while transportation is arranged. You may even transport the body in your own vehicle. For more information visit [**www.funerals.org/**](http://www.funerals.org/).

There are a number of options for final disposition of the body. Burial, cremation, and body donation are most common. Some people, however, may prefer unusual alternatives, such as becoming part of an artificial reef to help the environment, or to have their ashes launched with others for “perpetual” orbit in space. Culture, religion, and personal preference all play a role in determining what the deceased and family want.

ARRANGING THE SERVICE

Once the body has been moved, you need to begin planning the funeral or memorial service in accordance with the wishes of the deceased. Hopefully, plans have been made ahead of time. If not, find someone to assist you, for example your minister, a trusted friend, or a family member. If the funeral home or mortuary has not been selected ahead of time, a funeral or memorial society can help. To find one in your area, visit www.funerals.org or call 1-800-765-0107.

You need to tell family and friends about the death and the service. Ask for help with this task by calling three to five reliable contacts and asking them to each call three to five others. Your faith community can help spread the word among its membership, and announcements can be posted in the newspaper or sent through e-mail. If the deceased was working or volunteering at the time of the death, alert someone at their workplace.

If the death occurs in a distant community, you may be eligible for a discounted airline ticket. Travel agents and airline representatives may ask to see a copy of the death certificate. Most employers allow you to take funeral leave. Ask about your benefits, and don't hesitate to ask to take vacation or sick leave if you need more time off.

PRACTICAL MATTERS

After you have surrendered the body, there are many tasks to complete. Survivors are often at a loss for how to proceed. Here are the steps to follow:

Obtain certified copies of the death certificate.

The family doctor or medical examiner will supply and sign the death certificate within twenty-four hours of death and state the cause of death. The remainder of the form usually is completed by the mortuary handling the final affairs and filed with the state registrar. You will need a certified copy of the death certificate every time you apply for benefits or need proof of the death. It is best to get ten to fifteen certified copies, depending on the complexity of the estate. Photocopies will not be accepted.

Obtain certified copies of the marriage certificate.

If you are the spouse, you may need proof of marriage before you can inherit from the estate, existing policies, or investments. You will also need proof of marriage when applying for Social Security benefits.

Death and marriage certificates are kept by the state where the death or marriage occurred. Visit **www.cdc.gov/nchs** for state-by-state information on requesting certified copies of death and marriage certificates.

Notify the lawyer or executor of the estate.

Settling an estate can be a complicated affair. There may be a need for legal advice on matters such as:

- Re-recording of property deeds
- Disposition of stocks and bonds, investments, savings and checking accounts, and other assets
- Disbursement of the deceased's estate

Contact the local life insurance agent or the home office of the life insurance company.

Locate insurance policies for death benefits. You usually need to show two documents: a death certificate and a statement of claim. Companies reserve the right to request further information. Claims should include the:

- Full name and address of the deceased
- Policy number(s) and face amount(s)
- The deceased's date and place of birth as well as the date, place, and cause of death
- The deceased's occupation and date last worked
- The claimant's name, age, address, and Social Security number

Contact the Social Security office.

You will need to contact the Social Security office to check eligibility for lump-sum benefits and to inquire about monthly benefits. Remember, you must apply for Social Security benefits. They are not automatic. Delays in applying may result in the loss of certain benefits. Visit **www.socialsecurity.gov** or call 1-800-772-1213 for more information.

When applying for Social Security benefits, you will need:

- A certified copy of the death certificate
- The deceased's Social Security number
- Approximate earnings of the surviving spouse in the year of death
- Record of deceased's earnings in the year prior to death (W-2 form or tax return)
- Social Security numbers of the surviving spouse and minor or disabled children (disabled before age twenty-two and who remain disabled)
- Birth certificates of the surviving spouse and minor or disabled children (disabled before age twenty-two and who remain disabled)
- Proof of marriage (certified copy of certificate)
- Proof of citizenship
- Picture identification
- Checkbook or bank account number so that benefits can be deposited directly into your account.

Explore eligibility for Civil Service and Veteran's benefits.

Survivors of civil service or federal workers may be eligible for benefits if the deceased was the spouse and he or she died after eighteen months on the job.

Visit **www.opm.gov** or call 1-888-767-6738 for more information.

If the deceased was a veteran, he or she is entitled to burial benefits in a national or state Veteran's cemetery. For more information, visit **www.cem.va.gov** or call 1-800-827-1000.

Contact the employer for death benefits.

If your loved one was employed at the time of death, contact the employer to check for death benefits.

Alert banks, credit card companies, automatic payments plans, and subscriptions services.

Notify the companies with which the deceased had regular service. Call any banks where the deceased had accounts. It is best to name a beneficiary on individual accounts before death occurs. However, if this has not been done, the surviving spouse or family member may complete an affidavit from the bank. Alert credit card companies. If you held a joint account with the deceased, the company may want to issue you a new card.

If the deceased ordered medications by mail, you should cancel the service. Cancel or change the name on any automatic bill-paying services and magazine and newspaper subscriptions. Any mail addressed to the deceased should be marked “Deceased - Return to Sender” and given to the mail carrier or post office.

HANDLING YOUR EMOTIONS

People react differently to a death. Even when death is expected, the emotional impact of losing a loved one can be overwhelming.

In the midst of all the tasks, you may experience a range of emotions including sadness, confusion, loneliness, guilt, anger, and anxiety. You may feel like you are on an emotional roller coaster. One day you may feel completely lost, the next day you may feel normal and productive, and the next day you may feel down in the dumps. These changing feelings are a normal part of the grieving process.

Read Booklet 5 in this series for more information on grief, the healing process, and when to get help.

*Every stroke of my brush is the overflow
of my inmost heart.*


—Sengai

CHECKLIST

- ☐ Call your minister, family members, or friends to be with you immediately after the death of your loved one.
- ☐ Call the funeral home, mortuary, or medical school about transporting the body.
- ☐ Contact the people who can help arrange the service.
- ☐ Notify the local newspaper of the death and include information in the obituary on location of service, donations, flowers, etc.
- ☐ Alert other family, friends, workplace, and faith and volunteer communities about the death.
- ☐ Obtain ten to fifteen certified copies of the death certificate, depending on the complexity of the estate.
- ☐ Contact the Social Security office.
- ☐ Contact the life insurance company of the deceased.
- ☐ Explore eligibility for Civil Service and Veteran's benefits.
- ☐ Notify the lawyer or executor of the estate.
- ☐ Alert credit card companies.
- ☐ Cancel prescription, newspaper, and other subscriptions.
- ☐ Cancel automatic bill payments.
- ☐ Read booklet 5 in this series for more information on grief, the healing process, and when to get help.

IMPORTANT PHONE NUMBERS

Use this space to write down contact information for family, friends, funeral home or mortuary, employer, minister, lawyer, bank, credit card companies, and other service providers.



Use this logbook to track your calls.

Date

Person called

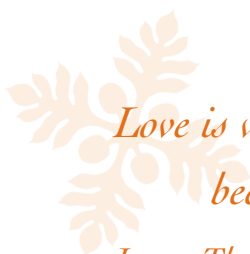
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Purpose of call

Outcome

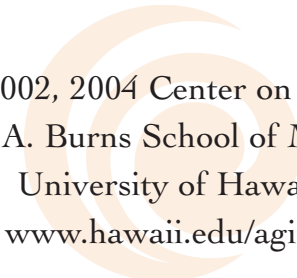
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*Love is what you've
been through with somebody.*

—James Thurber



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HELP FOR THE BEREAVED



The Healing Journey

THE COMPLETE LIFE SERIES

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Booklet 2 - Planning Ahead: Funeral and Memorial Services. *A workbook to document your funeral or memorial service preferences ahead of time. Includes tips for consumers.*

Booklet 3 - Preparing to Say Good-bye: Care for the Dying. *Learn about common symptoms experienced by dying people and what you can do to make the dying person more comfortable.*

Booklet 4 - When Death Occurs: What to Do When a Loved One Dies. *A guide to help you get through the hours, days, and weeks following a loved one's death.*

Booklet 5 - Help for the Bereaved: The Healing Journey. *Learn about the common expressions of grief, the healing process, and when to get help.*

All five booklets can be downloaded from
www.hawaii.edu/aging

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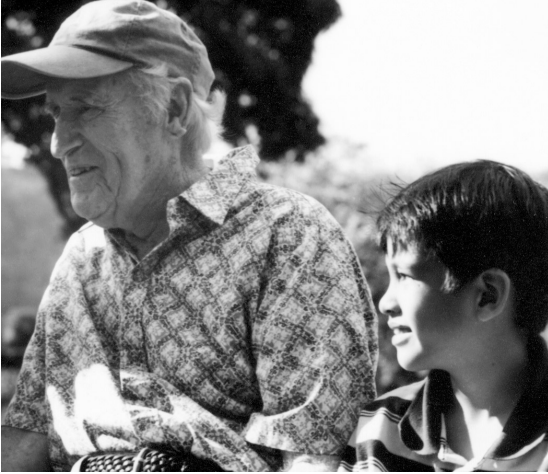
THE HEALING JOURNEY

Grieving the loss of a loved one is a journey toward healing. In the beginning stages, the road may seem rocky and difficult to travel. At first, it may feel impossible to see the path ahead. Over time, however, the journey becomes easier and healing begins.

In this booklet, you will learn how experts describe the grieving process, or the journey of grief. You will learn what experts feel is normal grieving and what is abnormal or complicated grieving. As you learn what is considered normal, you will feel more comfortable with the expressions of grief.

Keep in mind, however, that each person's grief is unique. A bereaved person may or may not experience all of the feelings described. Experiences and expressions of grief are as individual as fingerprints. Gender, culture, personality, earlier losses, beliefs, values, and religion are among the many factors that influence the way in which we grieve. In fact, most people never get over their loss completely. Rather, they can come to grips with the loss and move on.

There is no "right" way to grieve and no specified length of time required for the grieving process. Experts agree that individuals emerge from their grieving when they reach a state of acceptance and feel a re-emergence of hope, however long it takes.



*When we are no longer able
to change a situation, we are challenged
to change ourselves.*

—Viktor Frankl

COMMON EXPRESSIONS OF GRIEF

Grief is expressed in different ways. Some people want to talk about their grief. Others may keep to themselves for a period of time. Some people may be very emotional or cry a lot. Others may not shed any tears. Returning to daily routines as soon as possible may be comforting to certain people. Others may withdraw.

Regardless of expression, remember that grieving is about change and movement. Finding safe and acceptable ways to express grief and move through the grieving process is what is important.

Each person's journey of grieving is unique. But there are some common **emotional** expressions of grief. These include:



Sadness. Waves of sadness are extremely common and sometimes can seem unbearable.

You may feel that you will never be happy again.

Over time, however, the intensity of sadness lessens.



Loneliness. The loss of a loved one causes feelings of loneliness. Returning to an empty house and revisiting places that you and the deceased once frequented may trigger these feelings. Evenings and weekends may be the most difficult, as there is less activity and more quiet time to think about the deceased and to feel his or her absence.



Anger. You may feel anger toward the deceased, the doctors, family members, or friends. You may even be angry with God. Anger may be turned inward and result in depression, withdrawal from activities and work, or physical illness.



Guilt and Blame. You may go through a series of “if onlys.” Thoughts of “I should have done more” or “If only I had...” are common. Blame may be directed at others or yourself. These thoughts are common. If these thoughts last a long time, however, they may result in a lack of self-forgiveness and may complicate grief.



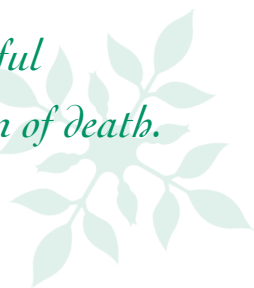
Anxiety. The death of a loved one often involves the death of plans for the future together. You may feel completely lost and off-balance. These feelings may be accompanied by intense anxiety over what the future may hold.



Relief. If the death has followed a long illness, there may be relief that it is finally over. This is normal, and there is no need to feel guilty.

*Guilt is perhaps the most painful
companion of death.*

—Elisabeth Kübler-Ross





Thankfulness. You may feel that the death was a blessing. This does not mean you do not feel sad. People need permission to feel OK about a death. Gratitude and thankfulness are great healers.



Emotional Ups and Downs. The initial reaction to a death may be shock and denial, followed by intense grieving, pain, working through grief, and readjustment. It is common to have mood swings. One day you may feel back to normal, and the next day feel down in the dumps. Anniversaries of the death, birthdays, holidays, seeing someone who looks like the person, or visiting a familiar place may trigger an “emotional down.”

There are several **physical** responses, too.



Insomnia and Bad Dreams. Sleep is essential for your well-being. However, insomnia and bad dreams are common, particularly in the first stages of grieving. Vivid dreams involving death or about the deceased are frequently reported and may be upsetting. These are a normal part of adjustment.

***Tip:** Relaxation techniques, exercise, meditation, music, or mild sedatives may help you sleep better. Also, having an opportunity to “talk out” your dreams can help you move through the grieving process.*



Physical Complaints and Loss of Appetite.

Physical complaints are common, such as stomach ache and tightness in the chest and throat. You may feel as if your stomach is “tied in knots.” You may not feel hungry.

***Tip:** Eating several small meals may be easier than eating fewer big meals. Keep nutritious snacks around the house. Accept food that is brought to you by friends and neighbors. Spend mealtimes with family or friends.*



Confusion. Confusion, memory loss, and inability to concentrate often are seen in the early stages of grief. You may feel as if you are going crazy. You may experience a lack of concentration or inability to do routine tasks. The initial intense emotions of grief temporarily affect the way your mind and body function. Normally, these are temporary conditions. If they persist, this may signal depression and a need for professional help.

***Tip:** It is helpful to acknowledge this response to grief and understand that this response is common. Receiving outside help can ease feelings of helplessness and confusion.*

*In the end, it's not the years
in your life that count,
it's the life in your years.*

—Abraham Lincoln

SIGNS OF NORMAL GRIEVING

- ☐ I can experience moments of joy, although I miss my loved one and often feel sad.
- ☐ I sometimes feel angry or anxious, but I am able to share how I feel with others.
- ☐ I can ask for help and/or receive support when others offer it.
- ☐ At times I feel guilty and sad, but I am still able to enjoy life.
- ☐ At times I feel alone, but I know I can manage after my sadness lessens.

These are all signs of normal grieving. You are handling your grief well.

MYTHS ABOUT GRIEF

There are a number of commonly held misunderstandings about grief, which can present significant barriers to someone who is grieving. The statements below are not helpful!

MYTH 1: You should be over this by now.

MYTH 2: Time heals all wounds.

MYTH 3: If you're not crying, you're not really grieving.

MYTH 4: Men are not very good at grieving, and real men shouldn't cry.



“You should be over this by now.” WRONG!

Grieving people need a lot of support over a long time. Some cultures have a set period of mourning, after which the person is expected to get on with life.

Although these traditional periods of mourning can help with the grieving process, they may overlook the fact that everyone's grief is unique and is influenced by many factors.

It is generally true that the passage of time lessens the extreme feelings of sadness. But the feelings may never disappear entirely. Experts now believe that we do not get over the loss, but rather adapt and integrate the loss into our lives.



“Time heals all wounds.” WRONG! Time may never fill the emptiness caused by the loss of someone close to us, but it can lessen the harsher feelings that come in the first year of grief.



“If you’re not crying, you’re not really grieving.” WRONG! Although Western culture has become much more supportive of public displays of emotion, there are people who do not cry after the death of someone they love. Although the majority of these appear to be men, some women do not express their emotions through crying either. In addition, older people may be more reserved about public expressions of emotion than younger people.

Although crying readily expresses emotion and releases energy, crying in and of itself does not help to complete the tasks necessary to reinvest in life. Some people can, and do, express a great depth of emotion and never cry. Crying is only one way to express the depth of emotion related to the death of a loved one.

*Each difficult moment has the potential
to open my eyes and open my heart.*

—Myla Kabat-Zinn





**“Men are not very good at grieving” and
“Real men shouldn’t cry.” WRONG!**

Oftentimes, men may feel restricted from sharing because of social, gender, or cultural expectations. Men may tend to hold back their emotions. Women often are seen as more ready to accept help and express emotion, two things that are critical in the process of grieving. Since men are perceived as less willing to accept help and express their emotions, they are often seen as having more difficulties in dealing with their grief. However, this generalization is not always true, and this stereotype is not helpful. Both men and women should be offered help and support during this time.



A TIMETABLE FOR GRIEF?

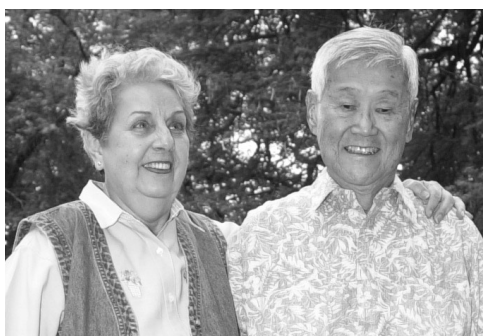
The following timetable describes a general process through the first two years of grieving. Many people begin to grieve long before the death actually occurs. Remember, however, this timeline is meant to be a general guide. Grief truly has no “time limit,” or clear-cut stages to pass through. Each person and situation is different, so allow yourself and others to grieve in their own way.





Month 1. In the first month following a death, you may be so overwhelmed with visitors, phone calls, funeral arrangements, and other tasks that you may not have time to experience your loss. The shock caused by the death of a loved one can last well beyond the first month, particularly if the death was sudden, violent, or especially untimely.



Month 3. Many people feel that the three-month mark is an especially challenging point in the grieving process. At this point, the numbness and shock may have worn off, and the telephone calls and visitors may have stopped completely. There may be a lot of pressure from family and friends to resume normal activities and to “get over” your loss. However, you may still be coping with the death of your loved one and may need more time to come to terms with your loss.



 **Months 4 Through 12.** By this point, hopefully you will begin to have more good days than bad. However, you will still be learning how to incorporate your loss and continue to live your own life. It is normal to still feel intense emotion and sadness from time to time. Remember, this is normal and is not a setback.

 **First Anniversary of the Death.** Reactions to the one-year anniversary of the death may begin days or weeks before the actual date. You may mentally relive those last difficult days. Even if you have been doing very well toward the end of the first year, you may be surprised at how intensely the one-year anniversary affects you. It is OK to talk about your feelings and to seek additional support during anniversaries.



The Second Year. Most grieving people agree that it takes at least two years to start feeling like they have established workable new routines and a revised identity without the deceased person. Many of the tasks of the second year have to do with re-assessing goals, discovering or developing new abilities, and creating a meaningful lifestyle for yourself.



Significant Anniversaries. Significant days that may be difficult include holidays, birthdays, wedding anniversaries, and family and school reunions. Also, significant dates in the course of the illness, such as the date of diagnosis and the date of death, can be especially challenging. Try to rely on the support of family and friends during this time.



Future Years. Don't be surprised if you feel periods of sadness years after the death of your loved one. Memories can be rekindled without warning. Don't try to suppress them. You are alive. Enjoy the gift of life, and celebrate the memories.

*The journey of a thousand miles
must begin with a single step.*

—Lao Tzu

ABNORMAL OR COMPLICATED GRIEF

In the process of healthy grieving, most people ultimately reach a state of acceptance. This may take a year or two, but you will notice observable progress.

Grief becomes complicated when you become stuck in the process of resolving and accepting the loss. Grief can become abnormal when you do not want to talk about your feelings and let go of your loved one.

The following is a list of signs and symptoms that **MAY** signal complicated grieving. Many of these symptoms will occur in the early months following a death. But if they persist, you should seek additional support.

Physical Problems

- Persistent weight loss or weight gain
- Alcohol or drug abuse
- Significant memory problems
- Prolonged sleep disturbances
- Prolonged neglect of personal hygiene and health

Functional Problems

- Continued inability to care for oneself
- Continued inability to care for one's family
- Continued inability to function in society

Emotional Problems

- Persistent disbelief about the death
- Preoccupation with thoughts about the deceased
- Prolonged feelings of numbness or hopelessness
- Searching and longing
- Behavioral problems (at work or at home)
- Talk of suicide
- Persistent hostility or anger toward loved ones
- Persistent disinterest in everyone and everything

WHEN AND WHERE TO SEEK HELP

Read through the list on the next page. If you check any of the boxes or experience any other sign of complicated grieving, you should seek help. Examples of places to find help include:

- Your faith community
- Your physician
- A bereavement support group, which may be found through a health care provider, hospice, or church in our neighborhood
- On the web, at

www.griefnet.org

www.centerforloss.com

www.growthhouse.org/death.html

SIGNS OF ABNORMAL GRIEVING

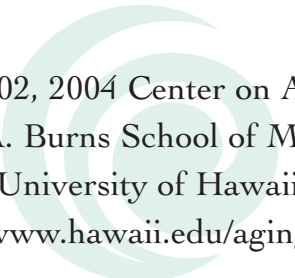
- ☐ I am unable to express my feelings.
- ☐ My health seems to be getting worse over time.
- ☐ I have no appetite and have been losing weight.
- ☐ I have been overeating and am gaining weight.
- ☐ I have thoughts of ending my own life.
- ☐ I feel responsible for my loved one's death.
- ☐ I feel sad and alone most of the time.

Checking any of the boxes above may indicate a need for professional help. Talk to your doctor, clergy person, or health care worker.

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*Tears are the prayer beads of us all,
men and women, because they arise
from a fullness of the heart.*

— Edward Hays



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