

November 2000

Choices and Conversations

Aging
2000

A GUIDE TO END OF LIFE CARE FOR RHODE ISLAND FAMILIES



Published by Aging 2000

Printing of the guide sponsored by
Blue Cross and Blue Shield of Rhode Island and
BlueCHiP Coordinated Health Partners, Inc.

Funding for the Rhode Island Partnership to
Improve Care at the End of Life provided by
a grant from the Robert Wood Johnson Foundation

Contributors:

Joan M. Teno, MD, MS

Debra DeSilva

Therese Rochon, RNP

Brown University School of Medicine

Center for Gerontology and Health Care Research

Carol Cummins, M. Ed., MLIS

ProChange Behavior Systems, Inc.

Maureen Glynn, JD

RI Dept. of Attorney General

Kathleen McKeon

Rhode Island Department of Elderly Affairs

Jean Miller, RN, PhD

University of Rhode Island

College of Nursing

Rev. David Shire

Butler Hospital

Marsha Stephenson, RN, BSN

Hospice Care of Rhode Island

Editing and production:

Norwalk Communications, Inc.

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When we enter the world we're surrounded by the love and support of friends and relatives.

Don't we deserve the same when we leave?

If you are interested in improving end of life care, call Aging 2000.

Aging 2000 offers free workshops on *Advance Directives (Living Will and Durable Power of Attorney)*, *Understanding your Role as a Health Care Agent*, *Improving Communication with Your Physician*, *Understanding Your Medicare Choices*, and other topics. Call Aging 2000 at 401-521-7930 or (toll free) 888-684-7200 if you would like to host a workshop in your community. To find out more about Aging 2000 programs, log on to www.info@aging2000.org.

Dear fellow Rhode Islanders:

Dealing with a loved one's terminal illness is one of the most difficult experiences a family ever faces. We all want a peaceful end to life with care that honors the whole person - body, mind, and spirit – and that follows the choices and wishes of the dying. The purpose of this guide is to help you and your loved ones reach this goal.

Improving care at the end of life is a national issue. But here in Rhode Island, where we have the second largest concentration of elderly citizens in the country, we are particularly concerned. In fact, research conducted by Brown University and Aging 2000 last year with families of the deceased points out that there is much to be done here at home:

- Many consumers don't know how to get the information they need to help their loved ones get the care they want.
- Many consumers feel that physicians do not do a good job of keeping family members informed and involved in decision-making.
- Although 75 percent of people who died in nursing homes had either a living will or a durable power of attorney for health care in effect, family members reported that they had either no effect or caused problems in 40% of the cases.
- Half of the people who died experienced unnecessary pain, and two-thirds of them rated the pain as severe.

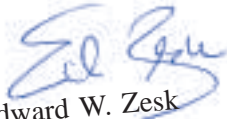
In response to these concerns, the Rhode Island Partnership to Improve Care at the End of Life was formed through a grant from the Robert Wood Johnson Foundation. Based at the Brown University Center for Gerontology and Health Care Research, the partnership also includes Aging 2000 and the Geriatric Education Center and College of Nursing at the University of Rhode Island. The partners are working together to find ways to improve the quality of care Rhode Islanders receive at the end of life.

continued...

There is much that health professionals need to do to improve care at the end of life, but there's also much that you and your family can do. Through careful planning, good communication, and the support of family and friends, it is possible to have a peaceful end of life on your own terms.

It is our hope that you will read and refer to this guide as a helpful resource in the future. Equally important, we hope it will stir discussion with your family, your friends, your doctor, and your spiritual counselors. While these conversations may be difficult, they are critical to making choices about your care that are right for you - and making sure your wishes are known and carried out.

Sincerely,



Edward W. Zesk
President
Aging 2000



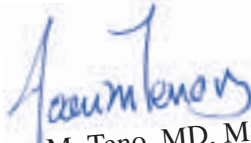
Ronald A. Battista
President
Blue Cross/Blue Shield
of Rhode Island



Sheldon Whitehouse
Attorney General
State of Rhode Island



Phillip G. Clark, ScD
Professor and Director
RI Geriatric Education Center
University of Rhode Island



Joan M. Teno, MD, MS
Associate Professor of Community Health
Brown University School of Medicine
Center for Gerontology and Health Care Research



Jean Miller, PhD, RN
Weyker Endowed Chair
in Thanatology
College of Nursing
University of Rhode Island

“I see the beginning of a culture that raises our expectations of what end-of-life care looks like....People are more assertively taking back responsibility to see that their loved ones are cared for in ways that are medically competent but are also tender and loving.”

**Ira Byock, MD, author of
Dying Well: The Prospect for Growth at the End of Life**

Introduction

Life at the beginning of the 21st century is clearly better than it was 100 years ago, but for many people *the end of life* has become more difficult than in the past – and more difficult than it needs to be.

While death will always be sad, there are ways to make it less difficult than it often is today for the person whose life is ending, and for his or her family.

The purpose of this guide is to explain some of the choices you can make – while you are still healthy – in order to make things easier for you and your family if you should become seriously ill. Even if you make choices that seem right today, it is likely that you will want to change them as you get older and things change in your life. That's why this process – called Advance Care Planning – should continue for the rest of your life.

Until recently, death was usually simple. Most people died at home after a short illness under the care of a family physician who could do little more than keep the patient as comfortable as possible.

Today, death is often more complicated.

Advanced medical treatment is available for many illnesses, but people still come to a point where curing their disease is no longer possible. New techniques are available to make people with terminal illnesses more comfortable in their remaining

days (see Dealing with Pain, page 13).

An even more difficult situation is becoming more common today: people are dying over months or years due to progressive diseases such as emphysema, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF) and Alzheimer's disease or other forms of dementia.

In the later stages of these diseases there is almost always something medical science can do to extend the patient's life, but the patient may not want to continue fighting. This is the point where patient, doctor and family need to come together to

make decisions that meet the wishes of the person whose life is ending.

These decisions involve your feelings about your quality of life. It can literally be a trade-off between length and quality of life.

Medical technology and new drugs can allow us to live longer. But many individuals dread the prospect of spending their final days in an institution depending on machines and receiving intensive treatment that only prolongs the dying process. Many of these people don't know that they can choose to change the focus of their care from treatment to comfort.

There is no right choice or wrong choice; it is your choice.

You can decide how to live the last days of your life, but you must think about these issues now and discuss them with your family and your doctor to make the best decisions for yourself and your loved ones.

This guide can help you and your family discuss these important decisions and make sure that your wishes are known and carried out when the time comes.

There is no right choice or wrong choice; it is your choice. You can decide how to live the last days of your life, but you must think about these issues now to make the best decisions for yourself and your loved ones.

Advance Care Planning

Planning in advance is the best way to make sure that you receive the health care you want – no more and no less – at the end of your life. Decisions that you make and share with others while you’re healthy will most likely be better than decisions that others make for you if you’re very sick.

The first and most important step in advance care planning is to think carefully about what you really want. Explore your feelings and values. Talk to people whose opinions are important to you: family members, physicians, friends, clergy, etc.

Here are some questions you may want to ask yourself:

- How do I feel about relying on machines in order to stay alive?
- Do I want everything possible to be done to delay my death?
- How do I feel about enduring pain and suffering at the end of my life?
- Would I prefer to die at home or in a hospital or nursing home?
- Is there someone I trust enough to make decisions about my care, and is that person willing to take on that responsibility?

Once you have a general idea about how you want to be treated at the end of your life, you may want to set up a plan that will help assure that your wishes are carried out.

Rhode Island law provides two ways for people to write down their wishes about the medical treatment they want to receive if they can no longer speak for themselves because of serious illness or injury. One is called a **Living Will**; the other is called a **Durable Power of Attorney for Health Care**. These legal documents are also called **Advance Directives** because they allow you to give directions about your care in advance of when you need it.

Having Advance Directives in place can help make sure that you get the care you want - whether you want to receive all possible treatments to keep you alive or you want to have limitations placed on treatment at the end of your life. You can have a Living Will, a Durable Power of Attorney for Health Care, or both.

If you are ever admitted to a hospital, you will be asked if you have any Advance Directives in place and you will be given information about them. It would be better to think about these issues beforehand, so you will

not have to deal with them at a time when you are sick and under great stress.

Remember, you are not required to have Advance Directives, but it’s a good idea to understand them so you can make a choice that’s right for you:

A **Living Will** tells your doctors what you want them to do – and what you want them not to do – if you should become terminally ill and unable to speak for yourself. It sets forth your choices about what kinds of care you want and how long you want care to be continued.

Before preparing a Living Will it is very helpful to discuss your wishes with your doctor to be sure that both you and the doctor have the same understandings about what you want. Your doctor should also be able to tell you about various possibilities you should consider.

You may also want to discuss these sensitive issues with your family, close friends and/or clergy. It is particularly important that your doctor and close relatives understand and accept your wishes because their interpretations and agreement will determine how the provisions of the Living Will are carried out.

A **Durable Power of Attorney for Health Care** allows you to name a health care agent—usually a family member or trusted friend—to make health care decisions for you if you are unable to speak for yourself for any reason. The agent and your doctor will do their best to

follow your wishes when dealing with situations that no one thought about in advance.

You can personalize the document by adding instructions for your doctor which indicate your preferences regarding medical treatment. For example, if you are especially concerned about controlling pain, you can state that you want as much pain medication as necessary to keep you comfortable.

You need to be very careful in selecting the person to act as your agent. Find someone you can trust to have the understanding and emotional strength to carry out your wishes, remembering that you are potentially asking that person to take part in life or death decisions along with your doctor. Many people choose close family members, while others feel that relatives would be too emotionally involved. Once you have chosen the right person, make sure that your doctor and family are aware of your decision.

These documents are used only for the purpose of stating your health care wishes – they have nothing to do with money or property. You do not need an attorney or a notary to complete these documents; you just need two people to witness your signature. It can be helpful to get advice from people who are familiar with advance directives. (See sample documents beginning on page 21.)

Make sure you give copies of your Advance Directives to your doctor, your agent and any family or friends who should be aware of your wishes.

Frequently Asked Questions about Advance Directives

What types of decisions can I make in my advance directives?

You can give broad or specific instructions. For example, you can state that you do not want life-prolonging treatment if you will never recover your physical and mental health to live without constant care. Or you can state that you want your life prolonged as long as possible. You can also state that you wish to receive only care to make you comfortable (palliative care) if recovery is not possible.

What happens if I don't have an advance directive and become seriously ill or injured?

If there are no directives in your medical or hospital files and you have not appointed a health care agent through the durable power of attorney, your doctors, hospital staff and loved ones will do the best they can. Without clear direction from you, however, your spouse, child, or life-long friend may be forced to guess what you would want. And if your family and friends disagree about your desires, these important decisions are left to the physicians by default.

Even if you have told your family, friends and/or doctors what kinds of treatment you want, keep in mind that spoken statements will not carry the same legal force as written ones. If you want your wishes to be known and followed, it's best to have written and signed advanced directives in place.

How long is my advance directive in effect? What happens if I change my mind?

Your advance directives are in effect until you change or cancel them, which you can do at any time.

How can I best assure that my advance directives are honored?

The best way to insure that your directives are honored is to talk about your preferences with your family members and health care providers. It is also important to distribute your written directives. Keep the original and give copies of the signed documents to your proxy or agent (including alternates), your physician, and your hospital. Put a card or notation in your wallet or purse stating that you have an advance directive.

If you spend an extended period of time in another state, you should also complete advance directives that will be accepted there. You can get sample documents for other states by calling 1-800-677-1116 or by downloading them from www.partnershipforcaring.org on the internet.

I wish my parents had advance directives. How can I talk with them about their wishes?

Explain to your parents that you want to understand their wishes for end of life medical care so that you can protect their rights and honor their preferences. It's best to do this before a crisis occurs. Explore their feelings about end of life care while acknowledging the difficulty of the topic. Talk with them about how important it is to plan in advance and write things down so that others will not have to make assumptions about their wishes at a stressful time. It may help if you prepare your own advance directives along with them.

Making sure your wishes are followed

COMMUNICATING WITH YOUR DOCTORS

Just having an advance directive in place does not ensure that your wishes will be honored; you must communicate with your doctor about your wishes in advance. If you have specific wishes, you must make a plan that will ensure your wishes will be honored.

When critical decisions are made, you may be in a hospital or nursing home and your primary physician may not be involved in your medical care. It is important to talk to the physician in charge of your medical care about your advance directive and your treatment wishes. If that physician does not make time to listen to your concerns, find a physician who will listen to your concerns.

Having the right physician is an important step to ensure that your preferences will be followed (see box). Sometimes physicians may be too busy or won't take the time to listen to your concerns. While it is your right as a patient to get satisfactory answers about your health care, most people do not feel comfortable confronting a physician. Here are some tips:

- Ask the physician for a separate appointment to discuss your concerns.
- Write down your concerns and questions prior to the appointment.

- Step back and take a deep breath. Put your anger aside.
- Take a friend or relative to listen and take notes.
- Ask the physician to explain things that you don't understand
- Make sure you leave knowing what to do, what to expect, and when your next contact with the physician should be.

It is very important that you, your agent, family member or friend insist on establishing clear and ongoing communication with the doctor or doctors who are treating you. This is not always easy but it is essential to ensuring that your wishes are understood and respected.

If you make a good faith effort but still cannot work with a certain physician, you will need to involve another physician in your health care. Remem-

ber, it's your health and you are in charge.

IN AN EMERGENCY

Since medical crises often occur outside of the hospital (at home or in a nursing home, for example), ambulance and emergency medical professionals need to know your wishes for end of life care. For this reason, a special program called **Comfort One** has been developed for emergency service personnel by the RI Department of Health.

As a Comfort One member, you wear a bracelet that describes what kinds of care you want (and do not want) in certain medical situations. Emergency medical personnel throughout Rhode Island are trained to follow Comfort One instructions including instructions not to resuscitate.

To find out more about Comfort One, contact the Rhode Island Department of Health's Division of Emergency Medical Services at (401) 222-2401. You will need authorization from your doctor to take part in the program.

DO YOU HAVE THE RIGHT PHYSICIAN?

There are many doctors and other health care providers to choose from, so you should be able to find one who meets your needs.

- Does your doctor take the time to explain your medical condition in ways that you can understand?
- Does your doctor offer you treatment options, make recommendations and explain them clearly?
- Does he or she listen to your concerns and answer your questions fully?
- Does your doctor let you know what to expect?
- Can you reach your doctor when you need to?

If you cannot answer Yes to all or most of these questions, you may want to consider seeking a new physician.

Turning Points in Illness and Care

People who suffer from chronic degenerative diseases can reach a point where they feel that the benefits of treatment are no longer worth the pain or discomfort. If you believe you have reached such a turning point, it is important to tell your physician what you are feeling.

While it is possible that the turning point from a treatable illness to a terminal one has been reached, it is also possible that difficult medical treatments have made the situation seem worse than it actually is.

- Dealing with a serious illness can make you depressed, possibly to the point where you feel that life is not worth living anymore. Before acting on these feelings, however, check with a doctor to find

- What is your professional opinion about my condition?

Talk to your physicians about your concerns.

HAVE YOU REACHED A TURNING POINT?

Before taking any action you should be sure that you have considered all the options. Ask yourself the following:

- What is important to you?
- How is your illness now affecting you physically and emotionally?
- Is the number of good days far outnumbering the bad days?
- How do you feel about the medical treatment you have been receiving?
- Have there been difficult or painful side effects?
- How is this affecting your loved ones?

Before taking any action you should be sure that you have considered all the options.

- If you have reached such a point, you may wish to change the kind of treatment you are receiving, perhaps entering a hospice program. This is a very important decision that you should discuss with your family and physician.
- If you have a chronic progressive illness, there is usually not a specific time when it becomes terminal. It just slowly gets worse and you may reach a point where you simply don't want to receive any more treatment.

out if you have clinical depression – a psychological condition that can often be helped. Medications or counseling may set you back on a more hopeful track.

ASK YOUR PHYSICIAN:

- How am I responding to medical treatment?
- How can you tell if the treatment is working?
- What are my options? What are the benefits and risks of those options?

Seeking Spiritual Support

Attending to your spiritual needs during a serious illness can be helpful whether the illness affects you or a loved one, whether you are religious or not.

Recent studies indicate that for many terminally ill patients, spiritual concerns are of greater importance than issues regarding the dying process itself. Often people with serious illness are confronting important questions such as: *Why am I suffering?* *What gives my life meaning?* and *What is death?* During this time, spiritual concerns are also heightened for the person caring for someone who is ill.

priest, minister, rabbi, or other spiritual advisor is aware of the situation and can be contacted when they are needed. Hospitals, nursing homes, home care providers, and hospices are all willing to arrange for spiritual support through their own staffs or local religious organizations. Let your doctor or health care provider know your religious preferences and the part that spirituality plays in your life.

with a spiritual counselor. If you have questions about contacting a local advisor, call your diocesan or denominational office and ask their advice.

Spirituality is not only found in a conventional faith in God. For some, spirituality is found in a meaningful relationship with the natural forces of the universe. Even those without religious backgrounds can benefit from spiritual care. What's important is that people pay attention to their spiritual needs in ways that are personally meaningful and fulfilling. Attending to one's spiritual needs before you become ill is an important way to prepare for end-of-life concerns.

For many families, the process of preparing advance directives can raise important issues of values, faith and spirituality. For that reason, people often involve clergy or spiritual counselors in the decision. Doing so may be an important step towards understanding your spiritual values and, ultimately, preparing for a more peaceful end of life for you and your loved ones.

The dying process offers an opportunity for growth and transformation as central issues of the meaning of life are confronted.

Regardless of your approach to spirituality or your religious preferences, attending to your spiritual well-being can be an important part of end of life care. The dying process offers an opportunity for growth and transformation as central issues of the meaning of life are confronted. Attendance to spirituality can give comfort, acceptance and peace.

Families can plan ahead to assure that their loved one's

They may be able to help you by referring you to a spiritual counselor. However, you may need to make a point of asking for this support if it is not offered.

It's important to know that you need not be a part of a congregation to contact clergy or ask for support. Even families who are not actively involved in a church, synagogue or other place of worship may receive comfort and counsel by talking

Dealing with Pain

Too often, people in Rhode Island die in unnecessary pain. A *Brown University Center for Gerontology and Health Care* research study found that 50% of people had severe pain for one-half the time in their last week of life.

People do not have to die with this level of pain.

Research has shown that 90% of pain can be controlled in people who are dying of cancer. No one needs to die in excruciating pain.

*Most pain can be controlled.
If yours is not, demand better care!*

WHAT CAN YOU DO?

MANAGE YOUR PAIN.

DON'T LET IT MANAGE YOU.

To receive the degree of pain relief you (or a loved one) need and deserve, you need to take an active role and **demand better care!**

Here are some strategies that can help:

1. Work with your doctor and nurse.

You should be prepared to tell them the following about your pain:

- Where is the pain?
- When did it start?

- When do you get the pain? Is it constant or does it come and go?
- What does it feel like? (see Table 1)
- Does the pain stop you from sleeping? Does it wake you up? Does it stop you from doing your daily activities? Which ones?
- What makes the pain worse? (i.e. moving, coughing, walking)
- What makes the pain better? (i.e. lying down, music, heat or cold)
- How is this pain affecting other parts of your life?

- What have you done to help your pain? Did it help? What did not help?
- What medicine makes it better?

2. Expect your doctor and nurse to work with you.

They should be willing and able to explain:

- What is causing your pain?
- What is the treatment plan?
- What are the things that you should monitor and call the doctor or nurse about?
- What should you do if your pain worsens?
- When will they reassess how you are responding to your pain treatment?

3. Things You Can Do to Manage Your Pain:

- Keep a Pain Diary (see Table 2). Share it with your doctor or nurse to find and improve situations where your pain is worse than it should be.

Table 1:
Words to Describe Pain

- | | |
|-------------|------------|
| • Sharp | • Burning |
| • Aching | • Tingling |
| • Throbbing | • Shooting |
| • Pressure | • Stabbing |

- Use medications as instructed by your doctor or nurse. Don't take medication only when the pain is bad. For chronic pain, a constant level of medication is best.
- Ask your doctor or nurse for instructions on additional "break-through" doses you can take if the pain gets particularly bad.
- If a medication makes you feel sleepy or nauseated, tell your doctor. Alternatives can be prescribed.
- Tell your doctor or nurse about unusual pain. It may be something unrelated to your disease.
- If you are terminally ill, ask your physician to involve a hospice program to assist in pain management.
- If you have chronic pain, ask for a referral to a pain specialist or pain clinic.

- Distraction, massage and relaxation have helped many people relieve some of their pain.

FACTS AND CONCERNS ABOUT PAIN AND TREATMENT*

Concern:
I can only take medicine or other treatments when I have severe pain.

Fact: Pain is easier to control when it is mild than when it is severe, so don't wait. You should take your pain medicine regularly and as your doctor or nurse tells you. You can also use other treatments, such as relaxation and breathing exercises, hot and cold packs, as often as you wish.

Concern: *I will become "hooked" or "addicted" to pain medicine.*

Fact: Studies show that getting "hooked" or "addicted" to pain medicine is very rare. Remember, it is important to

take pain medicine regularly to keep the pain under control.

Concern: *If I take too much medicine, it will stop working.*

Fact: The medicine will not stop working, but sometimes your body will get used to it. This is not usually a problem with terminal pain treatment because the amount of medicine can be changed or other medicines added. Pain *can* be relieved, so don't deny yourself pain relief now.

Concern: *Pain is affecting all parts of my life.*

Fact: There is no question that severe pain does more than just hurt. It can affect your mood, your appetite, your ability to do things. You may become irritable or depressed, raising concern among family and friends. All of these are reasons why you should seek out and use medications to relieve your pain.

Table 2: Keep a record of your experiences with pain and medications. Share this information with your doctor to help manage your pain most effectively.

Date	Time	Pain Intensity*	Medicine Taken	What I was doing when pain began	Pain intensity one hour after taking medicine

*Estimate pain intensity on a scale of 1 to 10 with 1 being mild and 10 being very severe.

*Adapted from U. S. Department of Health & Human Services: Agency for Health Care Policy and Research, 1994.

Concern: *If I complain too much, I am not being a good patient.*

Fact: Controlling your pain is an important part of your care. Tell your doctor or nurse if you have pain, if your pain is getting worse, or if you are taking medicine and it is not working. They can only help you get relief if they know you are having a problem.

Concern: *Morphine is offered to patients only when death is expected very soon.*

Fact: It is not the stage of a terminal illness, but the degree of pain that dictates which medicines to use. Doctors start with the mildest medicine and if it works, stop there. If it doesn't they move on gradually, turning to morphine when it's appropriate. Some people never need morphine, while others will require it for quite a while. The truth is that you can live for a long time while receiving morphine.

Hospice Care

Although medical care has made great advances, people can reach a point where their disease becomes incurable. From that point on, care should be directed toward easing discomfort. This stage of life is called terminal illness and it requires a different kind of care that can be provided by specially trained professionals.

People who are terminally ill usually need relief from pain. They and their families also often need information as well as spiritual and emotional support.

Hospice, a special kind of health care, answers that need for many patients and families.

WHAT CAN HOSPICE DO FOR YOU?

Hospice provides emotional, medical, and spiritual support for you when you are terminally ill. The goal is to improve quality of life by offering ways to be comfortable. The focus of care is on the patient's comfort rather than curing the disease. Hospice helps your family cope with the difficulties in your care and acts as an advocate during this time of illness.

The goal of hospice is to make each day the best it can be for the patient, family and friends.

WHAT ARE THE VALUES THAT GUIDE HOSPICE CARE?

- The worth and importance of the individual
- Self-determination and choice for you and your family

- Quality of life
- Access to services that are suited to you
- Care that considers family
- Care that involves all members of the health care team

WHAT TYPE OF HELP DOES HOSPICE PROVIDE?

Hospice focuses on managing pain and promoting physical, emotional and spiritual comfort for the patient and his or her family.

The hospice team includes:

- A primary physician to plan and supervise care
- Registered nurses on call 24 hours a day, 7 days a week to oversee delivery of care
- Certified Nursing Assistants to provide personal care and light housekeeping
- Social Workers to provide emotional and educational support
- Volunteers to give family caregivers necessary time off and help with shopping and errands
- Spiritual and bereavement counselors

CAN YOU GET HOSPICE CARE IN A NURSING HOME?

Yes. Hospice care is available in nursing homes, assisted living facilities and acute care hospitals.

HOW MUCH WILL HOSPICE CHARGE ME?

Hospice services are covered by Medicare, Medicaid and most health insurance policies.

The hospice Medicare benefit includes coverage for certain medications, equipment and supplies in addition to team services.

What Hospice Is:

Hospice helps prevent and treat discomfort in people who are terminally ill.

Hospice focuses on quality of life for you and your family. It is interested in emotional, spiritual and social pain as well as physical.

Hospice is for people with any kind of terminal illness.

Hospice is a philosophy of care.

Hospice is a family-oriented program that helps families and/or friends to care for their loved one in their home.

Hospice is covered by Medicare, Medicaid and most other insurance providers.

Hospice values the worth and importance of the individual. It offers the hope of dignity and comfort.

Hospice is meant to provide months of care and support.

What Hospice is Not:

Hospice does not focus on curing illnesses.

Hospice does not look only at your medical condition. Your emotional wellbeing is also an important concern.

Hospice is not only for cancer.

Hospice is not just a place to send dying people.

Hospice does not substitute for the family or the family's care.

Hospice is not a financial burden on patients or families.

Hospice is not euthanasia.

Hospice is not just for the last few weeks or days of life.

A Dying Person's Guide to Dying

The following essay was written by Roger C. Bone, M.D., a physician who has since died of cancer. His thoughts, reprinted with permission from the American College of Physicians, may be inspiring and helpful to you or someone you love.

What I have to say is for the person who, like myself, is dying. We, too, need to plan – to think ahead in order to fashion, out of the time remaining, the best of what is possible.

As I am dying from cancer, I have learned some things that I think are important for a dying person to know in order to plan. I am a physician, but what I have learned has little to do with my medical training. I have learned this as a person; perhaps my medical experience was helpful because I have paid close attention to the actions and reactions of people around me.

First, it is likely that you will be surrounded by persons who mean well, but in the end, you must die your own death. Dying can be considered a journey one takes alone with a crowd. Family and friends are the first to gather around you, and they offer the most comfort.

Here are some pieces of advice to remember in those first few days after you learn the bad news.

- One or two people - probably family members - will make enormous personal sacrifices to help you. If you are married, your spouse is likely to do this, but don't be surprised if others - a daughter, a brother-in-law, or even a friend, step forward to offer extraordinary help. Be grateful and accept help, from whatever source, graciously.
- Some family members, but especially friends, will treat you differently. Even before you show signs of serious illness, people will have a different look in their eyes as they talk with you. You might consider this patronizing or over bearing. It may be difficult, but it is best to ignore their attitudes and treat them as you always have. They will come around to their normal selves when they get over the shock.
- Happily accept all gifts from family and friends. It makes them feel better and you might receive something you really like and appreciate.
- Don't be afraid to ask to be alone. We need time to be by ourselves. Some family and friends may feel driven to fill your every waking moment with activities; perhaps they are trying to 'take your mind off' your impending death, but they may also be doing the same thing for themselves.
- Be your own counsel. No one, including your physician, religious counselor, spouse, or friends can understand 100% what you want and need. It surprised me that some people seemed to "bully" me with advice when they learned that I was terminally ill. We should remember Immanuel Kant's advice to avoid accepting someone else's authority in place of our own powers of reason. We are the ones who should be considering alternatives and making choices. We can, and should, ask for advice. Make telephone calls and read books - but ultimately, we should decide.
- Slow down and ask your family and friends to slow down. There may not be a lot of time, but there is sufficient time in all but the most extreme cases to think, plan, prepare.

Be your own counsel. No one, including your physician, religious counselor, spouse, or friends can understand 100% what you want and need.

There are things you need to know from your doctors and other health care staff. You need not ask all of the following questions or ask them in this order. Still, these questions deal with crucial issues that need to be addressed and, hopefully, resolved.

WHAT IS MY DISEASE?

You should find out as much as possible about your disease. What it is it? How will it affect me? And very importantly, how will it cause my death? First, ask your physician. Additionally, many popular books are available in bookstores and libraries which can give you a basic sense of your disease process and disease terminology. National organizations, such as the American Cancer Society, and often local hospitals can provide brochures, video tapes, or even lay experts to help you and your family understand your particular disease. Ignorance is not bliss; the more you and your family know, the better able everyone will be able to cope with what is happening.

SHOULD I SEEK A SECOND OPINION ABOUT MY DISEASE AND MY CONDITION?

Seek a second opinion! A second opinion will relieve your mind and resolve doubts one way or another that a major mistake has not been made. More importantly, a second opinion will offer a slightly different perspective that may help everyone's understanding. Don't be embarrassed about asking for a second opinion or think that you will make your physician angry. Second opin-

Sometimes the hardest part about dying is the effect it has on your family and friends. Helping them deal with your death helps you find peace and comfort.

ions are perfectly acceptable, and many physicians are happy when their patients seek second opinions. The original diagnosis is usually confirmed, and you are then more prepared to follow prescribed treatments.

WHAT HEALTH PROFESSIONAL DO I ESPECIALLY TRUST?

Search for and then trust in a single individual. This does not mean you should not listen to all health professionals and follow reasonable directions and advice. But focus on one individual as the final helper. This normally will be the specialist physician in charge of your case. However, you may know your family doctor better than you know your cancer specialist. If this is the case, your family doctor may be the one to choose. But, if you do, make certain that your family doctor knows that he or she is serving that role.

WHY AM I GOING INTO THE HOSPITAL?

There are four basic reasons why a terminally ill person would be hospitalized, but not all four necessarily apply to every patient. They are:

- (1) to confirm the diagnosis and analyze how far the disease has progressed;
- (2) to provide treatment that can only be given in the hospital,

(3) to treat a severe worsening of the disease; and

(4) to treat the final phases of the disease, if this cannot be done at home or with hospice.

You should know which applies to you so that you can understand why things are done to you and what benefits you can expect.

WHAT ARE THE HOSPITAL RULES ABOUT TERMINALLY ILL PATIENTS?

Hospitals and medical centers have written rules and procedures that outline in detail how the hospital will deal with terminally ill patients. These are not 'treatment' rules. These protocols or guidelines, as they are called, deal with how to handle end-of-life issues, such as whether the patient (or the patient's family speaking for the patient) wishes extraordinary "heroic" measures to be used to keep the patient alive. Hospitals are obligated, and very willing, to share these protocols or guidelines with patients and families. Consider getting a durable power of attorney in which you name one or two people to make decisions or choices on your behalf if you should be incompetent or incapable of making decisions yourself. Read the 'Do Not Resuscitate' policies of the hospital. Death should be peaceful, and you should not ask for

anything that gives you prolonged agony.

You should be aware that nurses and other hospital staff may not know that you are terminally ill. This fact may not be written in your chart, which can lead to conflicts between families and hospital staff. The family may assume that everyone in the hospital shares their grief, and will not understand the work-a-day attitude of nurses, dietitians, or others. It is okay for the family to tell the hospital staff that you are dying since they may not know.

WHAT RESOURCES ARE AVAILABLE FROM THE HEALTH CARE COMMUNITY?

Most hospitals have many services available to patients and families to help with nonmedical aspects of your care. These include social services and psychological, financial, and religious counseling.

For example, a visit, before hospitalization, to the hospital financial counselor by a family member to check on insurance and payment plans is a wise move. In the rush to admit a patient, important information may not get recorded. A 15 minute meeting with counselors can avoid stress and anger over incorrect bills.

Similarly, meeting with the hospital social worker may be very helpful in arranging home care. Use these services!

WHAT CAN I DO IF IT SEEMS THAT NOTHING IS BEING DONE OR IF I DON'T UNDERSTAND WHY CERTAIN THINGS ARE DONE TO ME?

Hospitals, clinics, and doctors' offices can be confusing places. You can begin to feel you have no control over what is being done to you, and you may wonder if anyone really understands your case.

This is the time to call the health professional who is your primary contact - the one you decided you fully trust - your physician specialist or family physician. Ask this person to explain what is going on. Have him or her paged or even called at home if your situation is very upsetting. It is the physician's responsibility to help you, and he or she will not be angry that you called.

HOW WILL I AND MY FAMILY PAY FOR MY TREATMENT?

Financial professionals employed by hospitals understand billing and what may or may not be covered by Medicare, Medicaid, or private insurance. Consult them and be sure to ask every question to which you and your family need an answer. It is important that you and your family do not panic over billing. Ask for advice and help.

Sometimes the hardest part about dying is the effect it has on your family and friends. Helping them deal with your death helps you find peace and comfort. If you are not at peace with your death, ask the health professional you especially trust to help you

find peace. That person will help or will get whatever help is needed. After all, it is the goal of all health professionals to give you comfort and health during life and peace to you and your family at death.

For additional information visit www.acponline.org/public/h_care on the internet.

Advance Directive Forms

On the following pages you will find sample forms approved by the State of Rhode Island for both Durable Power of Attorney for Health Care and Living Will.

As noted in earlier sections of this brochure, it is very important for you to think carefully about what is important to you and to discuss your wishes with your physician before completing any advance directive.

You may also want to talk with family members, close friends and spiritual advisers.

You can change or revoke these documents at any time.

State of Rhode Island

STATUTORY FORM DURABLE POWER OF ATTORNEY FOR HEALTH CARE

WARNING TO PERSON EXECUTING THIS DOCUMENT

This is an important legal document which is authorized by the general laws of this state. Before executing this document, you should know these important facts:

You must be at least eighteen (18) years of age and a resident of the state for this document to be legally valid and binding.

This document gives the person you designate as your agent (the attorney in fact) the power to make health care decisions for you. Your agent must act consistently with your desires as stated in this document or otherwise made known.

Except as you otherwise specify in this document, this document gives your agent the power to consent to your doctor not giving treatment or stopping treatment necessary to keep you alive.

Notwithstanding this document, you have the right to make medical and other health care decisions for yourself so long as you can give informed consent with respect to the particular decision. In addition, no treatment may be given to you over your objection at the time, and health care necessary to keep you alive may not be stopped or withheld if you object at the time.

This document gives your agent authority to consent, to refuse to consent, or to withdraw consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition. This power is subject to any statement of your desires and any limitation that you include in this document. You may state in this document any types of treatment that you do not desire. In addition, a court can take away the power of your agent to make health care decisions for you if your agent:

- (1) Authorizes anything that is illegal,
- (2) Acts contrary to your known desires, or
- (3) Where your desires are not known, does anything that is clearly contrary to your best interests.

Unless you specify a specific period, this power will exist until you revoke it. Your agent's power and authority ceases upon your death.

You have the right to revoke the authority of your agent by notifying your agent or your treating doctor, hospital, or other health care provider orally or in writing of the revocation.

Your agent has the right to examine your medical records and to consent to their disclosure unless you limit this right in this document.

This document revokes any prior durable power of attorney for health care.

You should carefully read and follow the witnessing procedure described at the end of this form. This document will not be valid unless you comply with the witnessing procedure.

If there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

Your agent may need this document immediately in case of an emergency that requires a decision concerning your health care. Either keep this document where it is immediately available to your agent and alternate agents or give each of them an executed copy of this document. You may also want to give your doctor an executed copy of this document.

(1) DESIGNATION OF HEALTH CARE AGENT.

I, _____
(insert **your** name and address) do hereby designate and appoint:

(insert name, address, and telephone number of **one individual only** as your agent to make health care decisions for you.)

None of the following may be designated as your agent: (1) your treating health care provider, (2) a nonrelative employee of your treating health care provider, (3) an operator of a community care facility, or (4) a nonrelative employee of an operator of a community care facility.) as my attorney in fact (agent) to make health care decisions for me as authorized in this document. For the purposes of this document, “health care decision” means consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat an individual’s physical or mental condition.

(2) CREATION OF DURABLE POWER OF ATTORNEY FOR HEALTH CARE. By this document I intend to create a durable power of attorney for health care.

(3) GENERAL STATEMENT OF AUTHORITY GRANTED. Subject to any limitations in this document, I hereby grant to my agent full power and authority to make health care decisions for me to the same extent that I could make such decisions for myself if I had the capacity to do so. In exercising this authority, my agent shall make health care decisions that are consistent with my desires as stated in this document or otherwise made known to my agent, including, but not limited to, my desires concerning obtaining or refusing or withdrawing life-prolonging care, treatment, services, and procedures.

(If you want to limit the authority of your agent to make health care decisions for you, you can state the limitations in paragraph (4) (“Statement of Desires, Special Provisions, and Limitations”) below. You can indicate your desires by including a statement of your desires in the same paragraph.)

(4) STATEMENT OF DESIRES, SPECIAL PROVISIONS, AND LIMITATIONS. (Your agent must make health care decisions that are consistent with your known desires. You can, but are not required to, state your desires in the space provided below. You should consider whether you want to include a statement of your desires concerning life-prolonging care, treatment, services, and procedures. You can also include a statement of your desires concerning other matters relating to your health care. You can also make your desires known to your agent by discussing your desires with your agent or by some other means. If there are any types of treatment that you do not want to be used, you should state them in the space below. If you want to limit in any other way the authority given your agent by this document, you should state the limits in the space below. If you do not state any limits, your agent will have broad powers to make health care decisions for you, except to the extent that there are limits provided by law.)

In exercising the authority under this durable power of attorney for health care, my agent shall act consistently with my desires as stated below and is subject to the special provisions and limitations stated below:

(a) Statement of desires concerning life-prolonging care, treatment, services, and procedures:

(b) Additional statement of desires, special provisions, and limitations regarding health care decisions:

(You may attach additional pages if you need more space to complete your statement. If you attach additional pages, you must date and sign EACH of the additional pages at the same time you date and sign this document.) If you wish to make a gift of any bodily organ you may do so pursuant to the Uniform Anatomical Gift Act.

(5) INSPECTION AND DISCLOSURE OF INFORMATION RELATING TO MY PHYSICAL OR MENTAL HEALTH.

Subject to any limitations in this document, my agent has the power and authority to do all of the following:

(a) Request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records.

(b) Execute on my behalf any releases or other documents that may be required in order to obtain this information.

(c) Consent to the disclosure of this information.

(If you want to limit the authority of your agent to receive and disclose information relating to your health, you must state the limitations in paragraph (4) (“Statement of desires, special provisions, and limitations”) above.)

(6) SIGNING DOCUMENTS, WAIVERS, AND RELEASES. Where necessary to implement the health care decisions that my agent is authorized by this document to make, my agent has the power and authority to execute on my behalf all of the following:

(a) Documents titled or purporting to be a “Refusal to Permit Treatment” and “Leaving Hospital Against Medical Advice.”

(b) Any necessary waiver or release from liability required by a hospital or physician.

(7) DURATION. (Unless you specify a shorter period in the space below, this power of attorney will exist until it is revoked.)

This durable power of attorney for health care expires on _____.

(Fill in this space ONLY if you want the authority of your agent to end on a specific date.)

(8) DESIGNATION OF ALTERNATE AGENTS.

(You are not required to designate any alternate agents but you may do so. Any alternate agent you designate will be able to make the same health care decisions as the agent you designated in paragraph (1), above, in the event that agent is unable or ineligible to act as your agent. If the agent you designated is your spouse, he or she becomes ineligible to act as your agent if your marriage is dissolved.)

If the person designated as my agent in paragraph (1) is not available or becomes ineligible to act as my agent to make a health care decision for me or loses the mental capacity to make health care decisions for me, or if I revoke that person’s appointment or authority to act as my agent to make health care decisions for me, then I designate and appoint the following persons to serve as my agent to make health care decisions for me as authorized in this document, such persons to serve in the order listed below:

(A) First Alternate Agent:

(Insert name, address, and telephone number of first alternate agent.)

(B) Second Alternate Agent:

(Insert name, address, and telephone number of second alternate agent.)

(9) PRIOR DESIGNATIONS REVOKED. I revoke any prior durable power of attorney for health care.

DATE AND SIGNATURE OF PRINCIPAL

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY)

I sign my name to this Statutory Form Durable Power of Attorney for Health Care on

_____ (date) at _____ (city, state)

(You sign here) _____

(THIS POWER OF ATTORNEY WILL NOT BE VALID UNLESS IT IS SIGNED BY TWO (2) QUALIFIED WITNESSES WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE. IF YOU HAVE ATTACHED ANY ADDITIONAL PAGES TO THIS FORM, YOU MUST DATE AND SIGN EACH OF THE ADDITIONAL PAGES AT THE SAME TIME YOU DATE AND SIGN THIS POWER OF ATTORNEY.)

STATEMENT OF WITNESSES

(This document must be witnessed by two (2) qualified adult witnesses. None of the following may be used as a witness:

- (1) A person you designate as your agent or alternate agent,
- (2) A health care provider,
- (3) An employee of a health care provider,
- (4) The operator of a community care facility,
- (5) An employee of an operator of a community care facility.

At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury that the person who signed or acknowledged this document is personally known to me to be the principal, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney in fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, nor an employee of an operator of a community care facility.

Signature: _____

Residence Address: _____

Print Name: _____

Date: _____

Signature: _____

Residence Address: _____

Print Name: _____

Date: _____

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I further declare under penalty of perjury that I am not related to the principal by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature: _____

Print Name: _____

Signature: _____

Print Name: _____

LIVING WILL

DECLARATION

I, _____, being of sound mind willfully and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If I should have an incurable or irreversible condition that will cause my death within a relatively short time, and if I am unable to make decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort, or to alleviate pain.

This authorization

includes

does not include

the withholding or withdrawal of artificial feeding

(check only one box above)

Signed this _____ day of _____ (month), _____ (year)

Signature _____

Address _____

The declarant is personally known to me and voluntarily signed this document in my presence.

Witness signature _____

Witness signature _____

Address _____

Address _____

Resources for End of Life Care and Decision Making

ADVANCE DIRECTIVES

Aging 2000 One Richmond Square, Providence, RI – A local grassroots organization dedicated to informing consumers about the healthcare system and improving the healthcare of older adults. Aging 2000 conducts free workshops in the community regarding advance care planning, responsibilities as a health care agent, and other issues concerning the healthcare of seniors. Free publications and copies of advance directives forms available. (401) 521-7930 or (888) 684-7200.

Choice in Dying, Inc., 1035 30th Street NW, Washington, D.C. 20016. Provides copies of state-specific advance directive forms and counsels patients and families. Also provides a list of other materials such as educational videotapes and literature. (202) 338-9790 or (800) 989-WILL (9455).

Commission on Aging with Dignity, 7700 North Kendall Dr., STE 602, Miami, FL 33156. Provides copies of *Five Wishes*, a simple but comprehensive form which defines a broad range of end of life care wishes and which is valid under Rhode Island and Massachusetts health care statutes. (888) 5WISHES (947437) or www.agingwithdignity.org.

Partnership in Caring: America's Voices for the Dying - National non-profit organization devoted to raising consumer expectations and demand for excellent end of life care. Provides a wide range of resources and information. (800) 989-9455 www.partnershipforcaring.org

RI Department of Attorney General – 150 South Main St., Providence, RI 02903. Consumer Division 274-4400.

Rhode Island Department of Elderly Affairs, 160 Pine Street, Providence, RI – Provides copies of Living Will and Durable Power of Attorney for Healthcare. The Department's Legal Services Developer provides free educational presentations on

Advance Directives and may be called on for information and referrals on this issue. (401) 222-2880 or (800) 322-2880.

Your local synagogue, diocese or denominational office is also often a valuable source of information and personal counsel regarding advanced directives.

Publications

Advance Medical Directives: Something to Think About – Simply written introduction to advance medical directives. To order, contact Choice in Dying, 200 Varick Street, 10th Floor, New York, NY 10014-4810, 1-800-989-WILL (9455).

Shape Your Health Care Future with Health Care Advance Directives. AARP. To order, call 800-424-2277 or write AARP-AD, P.O. Box 51040, Washington, D.C. 20091.

BEREAVEMENT

AARP – provides grief information, programs, and three weekly online support groups. www.aarp.org/griefandloss.

Compassionate Friends - Grief information and support after loss of a child. www.compassionatefriends.org.

Rhode Island Department of Elderly Affairs – 160 Pine Street, Providence, RI. Maintains a listing of local support groups offered by senior centers and adult day service centers. (401) 222-2880 or (800) 322-2880.

Mental Health Association of Rhode Island's Grief and Loss Collaborative – 500 Prospect Street, Pawtucket, RI - provides information and referral to local mental health services and support groups concerning grief and bereavement. (401) 726-2285.

Webster's Death, Dying and Grief Guide – a comprehensive collection of internet resources with a holistic perspective. www.katsden.com/death/intro.html

Publications

Understanding the Grief Process. AARP Fulfillment EE01428, 601 E. St. NW, Washington, D.C., 20049. Request a free copy by asking for stock number D16832.

My Friend, I Care: The Grief Experience. This pamphlet may be obtained by writing to Barbara Karens RN, P.O. Box 335, Stilwell, KS 66085.

CAREGIVING

Family Caregiver Alliance- a comprehensive resource for long-term care information and adult caregiver support. www.caregivers.org

National Family Caregivers Association – Offers information, education, support, and advocacy for caregivers. www.nfcare.org.

Rhode Island Department of Elderly Affairs – 160 Pine Street, Providence, RI - offers referrals to local Caregivers Support Groups available at local senior centers. (401) 222-2880 or (800) 322-2880.

Respite Care Services, 83 Stewart Street, Providence, RI. Provides financial support for temporary relief of primary caregivers, assists eligible clients with daily maintenance of home, and provides companionship for elderly homebound residents throughout the state. (401) 421-7886 or (800) 445-2033.

Web of Care – an online community focused on home caregivers. Includes on line chat events, member support, and information. www.webofcare.com.

Publications

Mace, Nancy L., Rabins, Peter V., and McHugh, Paul R. **The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illness, and Memory Loss in Later Life.** Johns Hopkins University Press. 1991.

Morris, V. **How to Care for Aging Parents.** Workman Publishing. 1996.

Meyer, Maria and Derr, Paula. **The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers.** CareTrust Publications, LLC. 1998.

HOSPICE CARE

Hospice Cares - An interactive gathering place which promotes the hospice philosophy of care by offering a comprehensive database of hospice-related information available on the internet. www.hospice-cares.com/hands.html.

Hospice Helpline - provided by the National Hospice and Palliative Care Organization (NHO), offers information about hospice care in general and hospices in the community. (800) 658-8898.

Hospice Link – a nationwide toll-free service provided by the Hospice Education Institution to the general public and to health care professionals seeking referrals to local hospices and palliative care services or bereavement groups. Call (800) 638-6833.

Hospice Net – A website for patients and families facing life-threatening illness. Includes frequently asked questions about Hospice, pain management guides, how to relieve pain without medicine, prescription and non-prescription pain relievers. www.hospicenet.org.

Hospice of Kent County VNA, 51 Health Lane, Warwick, RI (401) 737-6050.

Hospice of Nursing Placement, 339 Angell Street, Providence, RI. (401) 453-4544.

Hospice Care of Rhode Island - Central Office
169 George Street, Pawtucket, RI
(401) 444-9070 or (800) 338-6555.

The Borden-Carey Building - Island Office
c/o Newport Hospital, 11 Friendship Street,
Newport RI (401) 845-1606

Philip Hulitar Inpatient Center
50 Maude Street, Providence, RI.
(401) 351-5570.

South County Office
143 Main Street, Wakefield, RI
(401) 444-9010.

Hospice of VNS of Greater RI, 6 Blackstone Valley Place, Suite 515, Lincoln, RI. 769-5670 or (800) 696-7991.

Hospice of VNA of RI, 157 Waterman Street, Providence, RI (401) 444-9400.

Last Acts – a national coalition to improve care at the end of life. A valuable resource for news updates and information on palliative care, family needs, service providers, education and training, and financing. www.lastacts.org.

National Hospice Organization (NHO). NHO web site dedicated to promoting and maintaining quality care for terminally ill persons and their families and to making hospice an integral part of the US health system. www.nho.org.

Northwest Hospice, 185 Putnam Pike, Harmony, RI. 949-2600.

VNS of Newport and Bristol Counties Hospice, 1184 East Main Road, Portsmouth, RI. (401) 682-2100.

LEGAL SERVICES

RI Bar Association's Legal Information and Referral Service for the Elderly – 115 Cedar Street, Providence, RI. Moderate to low income persons 60 or older may receive free or reduced cost legal help. (401) 521-5040.

Rhode Island Department of Attorney General – 150 South Main St., Providence, RI 02903. Consumer Division 274-4400.

Rhode Island Department of Elderly Affairs – 160 Pine Street, Providence, RI. The DEA Legal Services Developer helps elders obtain legal assistance. The developer provides public information on legal issues affecting older people and is available to speak at senior organizations. Call (401) 222-2880 or (800) 322-2880.

Rhode Island Legal Services – 56 Pine Street, Providence - provides free legal assistance. (401) 274-2652.

Senior Law: Elder Law and Legal Resources on the Web – Provides a wide list of resources regarding elder law and legal resources including Advanced Directives. www.seniorlaw.com/resource

LONG TERM CARE

Rhode Island Department of Elderly Affairs – 160 Pine Street, Providence, RI. Community based elder information specialists provide information and referrals regarding all aspects of local elder care. (401) 222-2880 or (800) 322-2880.

Rhode Island Department of Health, Division of Facilities Regulation – licenses and monitors the care in nursing homes. Provides a comparison of nursing facilities in five categories: administration, nursing, resident rights, food services, and environment. There are links on the website to helpful information on nursing homes, a discussion of how to choose a facility, and information on organizations that can help you make a sound choice. (401) 222-2566 or www.health.state.ri.us/hsr/facreg/

PAIN

American Pain Society – A multidisciplinary educational and scientific organization serving people in pain by advancing research, education, treatment and professional practice. www.ampainsoc.org.

Mayday Pain Resource Center (MPRC). Serves as a clearinghouse to disseminate information and resources that will enable other individuals and institutions to improve the quality of pain management. An index to more than 300 materials can be found on the site. www.cityofhope.org/mayday/

National Chronic Pain Outreach Association, 7979 Old Georgetown Rd., Suite 100, Bethesda, MD 20814. Serves as a clearinghouse of information related to chronic pain and provides written materials. (301) 652-4948.

Palliative Medicine Program at the Medical College of Wisconsin – an organization committed to improving care for the dying in America through the development, implementation, and dissemination of innovative educational and clinical care programs. MCW's website offers resource materials, information on analgesic guidelines, and information about institutional pain management. www.mcw.edu/pallmed

Partners Against Pain (a service of Perdue Pharma, L.P) - Hosts a website which offers information about professional education, manage-

ment tools, steps to control pain, patient education, and prescribing information.

www.partnersagainstpain.com/index

Publications

Taking Control of Your Pain. American Cancer Society and the Boston Cancer Pain Education Program. Available in English, Vietnamese, French, Creole, Portuguese, Chinese, Japanese, Spanish, or Russian. Call (800) 227-2345 and ask for ACS Code #MA-4501 or contact the New England Medical Center at www.cemmp@lifespan.org.

SPIRITUAL CARE

Rhode Island State Council of Churches, 734 Hope Street, Providence, RI. An ecumenical resource for Rhode Islanders of all faiths, providing referrals and resources regarding spiritual concerns. (401) 861-1700.

Your local synagogue, diocese or denominational office is a valuable source of information and personal counsel regarding end of life care.

ILLNESS SPECIFIC RESOURCES

AIDS

AIDS Project RI, 232 West Exchange Street, Providence, RI. Provides information, dental services, guidance with medical assistance, counseling, prescription assistance, housing assistance, heating assistance, education, hotline, and referrals. (401) 831-5522 or (800) 726-3010 (hotline).

AIDS Care Ocean State, 18 Parkis Avenue, Providence, RI. Provides housing, case management, and residential child care for high risk children. (401) 521-3603.

Matthew XXV HIV/AIDS Ministry, 791 Potters Ave., Providence, RI. Provides counseling, visitation, free food pantry, and one-on-one support services for patients and their loved ones. (401) 781-9451.

ALZHEIMER'S DISEASE

Alzheimer's Association, RI Chapter, 245 Waterman Street, Providence, RI. Provides information, education, support programs, referrals, personal guidance, and advocacy. (401) 421-0008, (800) 244-1428 or www.alzheimers.org.

Alzheimer's Disease Education & Referral Center (A service of the National Institute on Aging), P.O. Box 8250, Silver Spring, MD 20907-8250. Provides up to date information about the latest research findings and treatments. (800) 438-4380 or www.alzheimers.org.

CANCER

American Cancer Society, 400 Main Street, Pawtucket, RI. Provides information about all aspects of cancer diagnosis and treatment and provides referrals to local support services. (800) ACS-2345 or www.cancer.org.

American Society of Clinical Oncology (ASCO). Articles about end-of-life care, palliative medicine, and pain control are available through the "search" function on the ASCO web site. The site also contains a special section, "People Living with Cancer," which provides up to date information about cancer treatment. www.asco.org

Cancer Education Center of NE Medical Center. Information on cancer care and pain management. www.cemmp@lifespan.org.

Hope Center for Cancer Support, 297 Wickenden Street, Providence, RI. Runs a variety of support groups and workshops for cancer patients and caregivers and provides a free, comprehensive library of books, videos, and audio tapes about cancer. (401) 454-0404 or www.hopecenter.net.

National Cancer Institute, 31 Center Drive, Bethesda, MD 20892-2580. Resource for information about cancer treatment, screening, supportive care, and clinical trials. (800)-4CANCER or www.nci.nih.gov.

HEART DISEASE AND STROKE

American Heart Association, RI Chapter, 275

Westminster Street, Providence. Provides information about heart disease, treatment, and side effects as well as referrals to local support groups and medical services. (800) 242-8721 or www.americanheart.org.

American Stroke Association, RI Chapter, 275

Westminster Street, Providence, RI. Provides information and support services for stroke survivors and caregivers. 1-888-4STROKE or www.strokeassociation.org. (800) 553-6321
Warmline connects stroke patients and caregivers throughout the country to share information and support.

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