Health Literacy **Toolkit**

Better Communication for Better Care

The Rhode Island
Health Literacy Project

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Dear Physician/Provider:

The Rhode Island Health Literacy Project (RIHLP) would like to introduce the *Health Literacy Toolkit: Better Communication For Better Care.* The enclosed toolkit offers resources to help physicians/providers and their staffs address communication challenges that may result from patients' literacy levels or language/cultural barriers.

The RIHLP has devoted the first edition of this toolkit to the topics of health literacy, advance directives, and cultural competency. It currently contains the following materials, which we hope you will find useful in your practice:

- Information on health literacy, advance directives, palliative care, and cultural competency, with tips that physicians/providers and their staffs can use to improve communication with their patients for better health outcomes
- Forms to document the end-of-life discussion, durable power of attorney for healthcare, and a living will
- Additional resources for physicians/providers and patients, such as talking points, articles, and Web sites

As other topics are developed and sections are expanded in the future, we will provide you with new materials to include in your toolkit.

About the RIHLP
The RIHLP is a statewide coalition of public health, adult education, and medical organizations. The primary objectives of the coalition are: 1.) To collaboratively develop and execute initiatives aimed at increasing the health literacy level of all Rhode Islanders; and 2.) To increase the size of the population who understands health information and self-care instructions.

The RIHLP is pleased to have partnered with Blue Cross & Blue Shield of Rhode Island (BCBSRI) in the development of this toolkit. BCBSRI sponsored this project, and BCBSRI Provider Relations representatives will help to distribute the toolkit to practices throughout Rhode Island.

For More Information
If you have any questions or feedback about this toolkit, please contact your BCBSRI Provider Relations representative, or Loretta Becker, Health Literacy Program Manager, at (401) 459-1795.

Sincerely,

Lori Quaranta, M.P.H.
Chair, Rhode Island Health Literacy Project
(401) 459-5520

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Better Communication for Better Care:
A Health Literacy Toolkit for Healthcare Providers

How to Use the Health Literacy Toolkit

Read the toolkit to gain insight and knowledge about health literacy, advance directives, and cultural competency. By doing this you will:

- Understand how issues pertaining to health literacy can negatively impact the health of your patients.

- Be well prepared to have conversations about advance directives when you identify patients who would benefit, or when patients bring up the topic with you.

- Learn about reimbursement for advance directives discussions and guidelines for documenting the discussion in the patient's medical record.

- Learn how your Medicare patients can qualify for Blue Cross & Blue Shield of Rhode Island's (BCBSRI) Palliative Care Program and how BCBSRI provides payment coverage for additional services.

- Understand how to recognize cultural barriers that may affect patients' access to care and how to overcome them.

Use the resources provided in the toolkit and have copies of documents on hand for distribution to your patients, including:

- Rhode Island Durable Power of Attorney for Healthcare

- Living Will

- Supporting documents, as appropriate, from the Patient Resources section

If you have questions or feedback about the toolkit, contact Loretta Becker, Health Literacy Program Manager, at (401) 459-1795 or contact your BCBSRI Professional Relations Representative.

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Acknowledgments

The Rhode Island Health Literacy Project (RIHLP) would like to thank the following organizations and individuals for materials used in this toolkit. All materials were used with permission.

Better Communication, *Better Care*,
Provider Tools to Care for Diverse Populations by
Industry Collaborative Effort (ICE) (ICEforhealth.com)

Education for Physicians on End-of-Life Care (EPEC)
©EPEC Project, The Robert Wood Johnson Foundation, 1999

Your Life, *Your Choices*, a patient tool for planning
for future medical decisions, by Robert Pearlman, M.D. M.P.H.,
Helene Starks, M.P.H., Kevin Cain, Ph.D., William Cole, Ph.D.,
David Rosengren, Ph.D., Donald Patrick, Ph.D. M.S.P.H.

and

State of Rhode Island Department of the Attorney General

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Introduction to Health Literacy

Health literacy is the ability to read, understand, and use health information to make appropriate healthcare decisions and follow instructions for treatment.

- **How big of an issue is health literacy?**
  According to a 2004 report by the Institute of Medicine (IOM), nearly half of all adult Americans – over 90 million people – have difficulty understanding and acting upon healthcare information. The IOM also estimates that poor health literacy contributes $50 to $73 billion to the annual cost of healthcare in this country.

  Furthermore, a 2002 report by the Nellie Mae Education Foundation found that 47 percent of adult Rhode Islanders – an estimated 368,000 people – are lacking basic literacy skills, the highest percentage in New England. The report drew on data from the 1992 National Adult Literacy Survey.

- **Why is health literacy so important?**
  The National Women’s Health Report (October 2004) showed that, when compared to their peers with average health literacy skills, people with poor health literacy skills:
    - Are more likely to report poor health status
    - Are twice as likely to be hospitalized
    - Remain in the hospital more days per each admission
    - Have one more outpatient visit per year
    - Have more difficulty using metered inhalers
    - Have worse HbA1c levels
    - Are more likely to make medication errors
    - Are less likely to comply with recommended treatment

  Furthermore, today’s patients are asked to perform more complex self-care, have less face-to-face time with physicians/providers, and are increasingly seen as active consumers rather than passive recipients of healthcare.

For more information, visit the Rhode Island Health Literacy Project Web site at www.RIHLP.org.

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Purpose of the Health Literacy Toolkit

This toolkit was created to help physicians and their staff address the barriers in patient-doctor communication that can be attributed to patients’ literacy levels or language/cultural barriers.

This toolkit promotes:

- Awareness of the health literacy issue with tips doctors and their staff can use to improve communication with their patients for better health outcomes
- Importance of discussing end-of-life issues with patients and documenting advance directives in the patients’ charts
- Development of a culturally competent practice, which allows patients to access care in a welcoming and shame-free environment

TIPS FOR IDENTIFYING AND ADDRESSING HEALTH LITERACY ISSUES

Low health literacy can prevent patients from understanding their health care services.

Health Literacy is defined by the National Health Education Standards (*) as *"the capacity of an individual to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which are health-enhancing."*

This includes the ability to understand written instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex health care systems. Health literacy is not the same as the ability to read and is not necessarily related to years of education. A person who functions adequately at home or work may have marginal or inadequate literacy in a health care environment.

Barriers to Health Literacy

- The ability to read and comprehend health information is impacted by a range of factors including age, socioeconomic background, education and culture.
  Example: Some seniors may not have had the same educational opportunities afforded to them.
- A patient's culture and life experience may have an effect on their health literacy.
  Example: A patient's background culture may stress verbal, not written, communication styles.
- An accent, or a lack of an accent, can be misread as an indicator of a person's ability to read English.
  Example: A patient, who has learned to speak English with very little accent, may not be able to read instructions on a prescription bottle.
- Different family dynamics can play a role in how a patient receives and processes information.
- In some cultures it is inappropriate for people to discuss certain body parts or functions leaving some with a very poor vocabulary for discussing health issues.
- In adults, reading skills in a second language may take 6–12 years to develop.

Possible Signs of Low Health Literacy

Your patients' may frequently say:

- I forgot my glasses.
- My eyes are tired.
- I'll take this home for my family to read.
- What does this say? I don't understand this.

Your patients' behavior may include:

- Not getting their prescriptions filled, or not taking their medications as prescribed.
- Consistently arriving late to appointments.
- Returning forms without completing them.
- Requiring several calls between appointments to clarify instructions.

Tips for Dealing with Low Health Literacy

- Use simple words and avoid jargon.
- Never use acronyms.
- Avoid technical language (if possible).
- Repeat important information – a patient's logic may be different from yours.
- Ask patients to repeat back to you important information.
- Ask open-ended questions.
- Use medically trained interpreters familiar with cultural nuances.
- Give information in small chunks.
- Articulate words.
- "Read" written instructions out loud.
- Speak slowly (don't shout).
- Use body language to support what you are saying.
- Draw pictures, use posters, models or physical demonstrations.
- Use video and audio media as an alternative to written communications.

(*) Joint Committee on National Health Education Standards, 1995

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Tips for Better Communication from the AMA Foundation

The American Medical Association Foundation created the health literacy toolkit, *Help Your Patients Understand*. Here are some of the strategies suggested in that toolkit.

Employ the Teach-Back Technique

Do not simply ask a patient, “Do you understand?” Instead, ask patients to explain or demonstrate how they will undertake a recommended treatment or intervention.

If the patient does not explain correctly, assume that you have not provided adequate teaching. Re-teach the information using alternate approaches. Use analogies and living room language to teach difficult concepts.

Six Steps to Better Communication

1. **Slow down.** Communication can be improved by speaking slowly and by spending just a small amount of additional time with each patient. This will help foster a patient-centered approach to the clinician-patient interaction.

2. **Use plain, nonmedical language.** Explain things to patients as you would explain them to a family member.

3. **Show or draw pictures.** Visual images can improve the patient’s recall of ideas.

4. **Limit the amount of information provided, and repeat it**. Information is best remembered when it is given in small pieces that are pertinent to the tasks at hand. Repetition further enhances recall.

5. **Use the teach-back or show-me technique.** Confirm that patients understand by asking them to repeat back your instructions.

6. **Create a shame-free environment.** Make patients feel comfortable asking questions. Enlist the aid of others (patient’s family, friends) to promote understanding.

Checklist for Patient Understanding

At the end of each office visit, a patient should be able to answer the following questions:

- What health problems do I have and what should I do about them?
- Where do I go for tests, medicine, and appointments?

- How should I take my medicine?
  - When do I take it?
  - What will it do?
  - How do I know if it is working?
  - Whom do I call if I have questions?
- Other instructions
  - What to do?
  - How to do it?
  - When to do it?
- Next steps
  - When do I need to be seen again?
  - Do I have another appointment? If so, what is the date and time of the appointment?
  - What phone number do I call if I have questions?

Use the *"Ask Me 3"* Approach

The Partnership for Clear Health Communication encourages patients to ask their doctors three questions. The goal of the "Ask Me 3" questions is for the patient to elicit from the doctor – in the least amount of time – the most significant information about the patient's health status.

Answers to these three questions help engage the patient to partner with you in his or her care:

1. **What is my main problem?**
2. **What do I need to do?**
3. **Why is it important for me to do this?**

As a provider, you can offer the answers to these questions without being asked. For more information on the ASK ME 3 program, visit www.AskMe3.org.

Advance Care Planning

Introduction

Advance care planning is a process, not an event. It is the process of planning for future medical care in the event that the patient is unable to make his or her own decisions. During this process patients explore, discuss, articulate, and document their preferences.

The process helps patients:

- Identify and clarify their personal values about medical treatment
- Identify the care they would like, or not like, to receive in various situations
- Determine whom they would like to make healthcare decisions for them if they are unable to do so themselves. This person is the patient's proxy.

Benefits of advance care planning

Patients have the right to participate in their healthcare planning, while physicians have a legal and professional responsibility to assure this, even if the patient loses the capacity to make decisions.

Ideally, advance care planning would occur as a separate visit that involves a structured discussion and documentation with the patient and proxy. The process of determining patient preferences for treatment builds trust and a sense of teamwork between the patient, the proxy, and the physician in several ways, including:

- The invitation to discuss future care permits the patient to understand his or her own goals and values around end-of-life care
- The physician and proxy learn about those preferences
- The process relieves fear and anxiety through a spirit of frankness and openness
- As preventive medicine, advance care planning avoids future confusion and conflict

Role of physician in advance care planning

The physician plays an important role in initiating and guiding the advance care planning discussion. Since the physician is responsible for the actual medical orders, he or she needs to feel comfortable that the patient's goals and priorities are understood and can be carried out. The physician will be involved in only some, not all, stages of advance care planning.

It may seem that advance care planning is too idealistic or time-intensive to include in a busy practice. However, the process outlined in this toolkit is intended to provide a realistic framework for the routine and practical inclusion of the process in practice. The patient, family, and proxy can do most of the work without the physician if given the tools (see Patient Resources). Reimbursement for advance care planning discussion and documentation (evaluation and management code or E&M), as well for submitting a code allowing the plan to track the E&M as an end-of-life discussion, is available through Blue Cross & Blue Shield of Rhode Island (BCBSRI) for certain physician specialties for Medicare Advantage patients. For other plans, the time it takes to counsel and provide information about advance directives may be reimbursable by coding the complexity of the encounter. Check with the patient's health plan. See Additional Provider Resources for EPEC's reimbursing coding guide.

Role of patient, proxy, and family

The patient, proxy, and family can do most of the work without the physician if they are given the proper tools, such as *Your Life, Your Choices*, included in the Patient Resources section of this toolkit. Patients will also need copies of the living will and durable power of attorney for healthcare documents specific to the state in which they reside. You can obtain these from the Web sites of your state's Office of Attorney General, Department of Health, and some health plans.

Role of other healthcare professionals in the physician's practice

Other members of the patient's healthcare team – nurses, physician assistants, or social workers – can assist the patient with advance care planning. Once the patient's ideas have been gathered, the physician can focus on the core discussions in direct meetings with the patient, proxy, and family. Preparatory work done by office staff will permit these discussions to be direct and effective.

Timing is everything

Research shows that most patients believe that it is the physician's responsibility to start advance care planning and will wait for the physician's initiative. Advance care planning is most easily accomplished during stable health. However, in the face of life-threatening illness or other significant change in health status, advance care planning becomes even more necessary. Try to find a time when the patient's condition is relatively stable and the patient has reasonably adjusted to the new illness or circumstance.

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Five Steps to Advance Care Planning

Step 1: Introduce the topic

Most patients welcome the opportunity to discuss their preferences with their physician. As anyone may suddenly and unexpectedly become ill and incapacitated, routinely initiate the advance care planning process with every adult patient in your practice, regardless of age or current state of health.

- Supply the patient with values/beliefs worksheets and other advance directives documents.
- Set an appointment dedicated to the end-of-life care discussion and ask the patient to bring in their completed documents with them.
- Discuss palliative care options.

Step 2: Engage in structured discussions

- Develop an understanding of the patient’s values and goals related to health and illness. This can easily be achieved if the patient has completed the worksheets.
- Involve the potential proxy (decision maker) in the discussions and planning so that he or she can have a thorough and explicit understanding of the patient’s wishes.
- Consider enlisting the assistance of one or more members of the healthcare team to help the patient with his or her advance care planning.

Step 3: Document patient preferences

- Once the patient has completed his or her initial planning and the advance directive of their choice (living will, durable power of attorney for healthcare, or both), the attending physician should sit down with the patient and proxy to review the advance directives and ensure there are no inconsistencies.
- Enter the directives and any related orders into the medical record.
- Ensure the relevant healthcare providers know of the advance directives and palliative care decisions.
- Ensure the patient understands that at every encounter with a healthcare provider or hospital, they should relate the fact that an advance directive exists. The proxy and the patient should each keep a copy of the advance directive, in an accessible place, not a safe deposit box.

Step 4: Review and update the directive

- Revisit the subject of advance care and palliative care planning on a periodic basis, particularly with major life or health changes.

Step 5: Apply prior directives to actual circumstances

- Most advance directives go into effect when the patient is no longer able to direct his or her own medical care.

- Capacity for decision making is different from global abilities to handle one’s affairs.
- Do not presume that patients who are very ill lack ability to make decisions.
- Know who the “default” proxy decision maker will be if the patient has not designated one.

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Guidelines for Reimbursement and Documentation

Effective April 1, 2006, BCBSRI began paying $10 to physicians who submit the code "S0257," along with an E&M code, for payment for advance directive and end-of-life counseling services for their BlueCHiP for Medicare patients.

This service would consist of an informative discussion by eligible physicians with their BlueCHiP for Medicare patients and/or family regarding treatment issues and options at the end of life. That discussion must then be clearly documented in the medical record.

Specialties eligible for reimbursement for this code include Primary Care, Oncology, Cardiology, Neurology, Pulmonary Medicine, and Geriatrics. Nurse practitioners and physician assistants within these specialties are also eligible for reimbursement.

For other insurance companies, please contact them directly to find out about their policies for reimbursement.

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Documenting the End-of-Life Conversation

It is important to document your patient's wishes concerning end-of-life care in the patient's medical record.

The patient's medical record should include a progress note as appropriate, and completed legal forms should be made a part of the record. Listed below are some recommendations to consider when documenting the conversation:

- Were legally acceptable formats of advance directives (i.e., living will, durable power of attorney for healthcare, do not resuscitate order for inpatients) discussed with the patient or with the patient and family?
- Were advance directive forms given to the patient?
- Were advance directives completed and signed by the patient?
- Were advance directives placed in the patient's medical record?
- Did the patient indicate specific limitations on care, designate a surrogate, or both?
- Did the patient and/or family indicate an understanding of the discussion?
- Was an interpreter requested or needed? If so, please note.

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Pearls and Potential Pitfalls

Pearls

1. Complete your own advance care planning.
2. Ask proxies if they are able and willing to fulfill the role.
3. Identify a patient's personal threshold for life-sustaining intervention.
4. Have validated worksheets available in the office. (See *Your Life, Your Choices*, in the Patient Resources section of this toolkit for sample worksheets.)

Potential pitfalls

1. Doing something to someone that he or she does not want.
2. Never introducing advance care planning.
3. Omitting the proxy from discussions between patient and physician.
4. Discussing too few possible clinical situations and treatment choices.
5. Avoiding advance care planning because the task seems too onerous.
6. Not informing loved ones/family of the patient's preferences.
7. Not knowing the patient's preferences.
8. Excluding from decisions compromised patients who retain decision-making capacity.
9. Assuming the content of an advance directive without reading it.
10. Allowing healthcare providers' own values and choices to interfere with the patient's expressed preferences.

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Advance Directives FAQ

Q. What is an advance directive?
A. Advance directives come in two forms: a durable power of attorney for healthcare decisions, and a living will. The state of Rhode Island encourages consumers to complete both documents.

Q. What is a durable power of attorney for healthcare decisions?
A. This document lets your patient name someone to make decisions about their medical care – including decisions about life support – if the patient can no longer speak for himself or herself, including any time the patient is incapacitated. (See “What is a healthcare proxy?”)

Q. What is a living will?
A. In Rhode Island, the living will is called the Rhode Island Declaration. It lets your patient state his or her wishes about medical care in the event the patient develops an incurable or irreversible condition and can no longer make medical decisions. The declaration becomes effective if, in your opinion, the patient would die without the use of life-sustaining medical care.

Q. What is a healthcare proxy (or agent)?
A. A healthcare proxy (a.k.a. “agent” or “attorney-in-fact”) is the person appointed by the patient to make medical care decisions if the patient is unable to make those decisions. The person named as the proxy should clearly understand the wishes of the patient and be willing to accept responsibility for making medical decisions. The proxy may be a family member or close friend whom the patient trusts to make serious decisions.

Q. Who should keep a copy of the patient’s advance directives?
A. The physician (by means of the patient’s chart), the patient, the proxy, and the patient’s lawyer, if any, should all keep a copy of the advance directive. The advance directive should be accessible in an emergency, and not held in a safe deposit box or safe. It is also advisable that patient carry a wallet card indicating that an advance directive exists and where it can be found.

Q. Is there any time in which a durable power of attorney for healthcare is not recognized?
A. Durable power of attorney for healthcare is not recognized by emergency services, rescue, or ambulance personnel. The one exception to this is transferring residents from nursing homes who have do not resuscitate orders. However, physicians attending terminally ill patients may be able to enroll the patient in the COMFORT ONE program. This program allows you to write a medical order directing rescue/ambulances service/emergency personnel not to start CPR. The patient signs the

form and you submit it to the Rhode Island Department of Health. The patient receives a COMFORT ONE bracelet (or necklace) to be worn at all times. For more information, contact the Rhode Island Department of Health.

Q. Can an advance directive be changed?

A. Yes, the patient can change their advance directive at any time, or make a different decision regarding their care, no matter what the advance directive contains, as long as he or she is physically and mentally competent to do so.

Rhode Island Durable Power Of Attorney For Health Care

AN ADVANCE CARE DIRECTIVE

"A GIFT OF PREPAREDNESS"

INTRODUCTION

YOUR RIGHTS

Adults have the fundamental right to control the decisions relating to their health care. You have the right to make medical and other health care decisions for yourself so long as you can give informed consent for those decisions. No treatment may be given to you over your objection at the time of treatment. You may decide whether you want life sustaining procedures withheld or withdrawn in instances of a terminal condition.

What is a Durable Power of Attorney for Health Care?

This Durable Power of Attorney for Health Care lets you appoint someone to make health care decisions for you when you cannot actively participate in health care decision making. The person you appoint to make health care decisions for you when you cannot actively participate in health care decision making is called your agent. The agent must act consistent with your desires as stated in this document or otherwise known. Your agent must act in your best interest. Your agent stands in your place and can make any health care decision that you have the right to make.

You should read this Durable Power of Attorney for Health Care carefully. Follow the witnessing section as required. To have your wishes honored, this Durable Power of Attorney for Health Care must be valid.

REMEMBER

i You must be at least eighteen (18) years old.

i You must be a Rhode Island resident.

i You should follow the instructions on this Durable Power of Attorney for Health Care.

i You must voluntarily sign this Durable Power of Attorney for Health Care.

i You must have this Durable Power of Attorney for Health Care witnessed properly.

i No special form must be used but if you use this form it will be recognized by health care providers.

i Make copies of your Durable Power of Attorney for Health Care for your agent, alternative agent, physicians, hospital, and family.

i Do not put your Durable Power of Attorney for Health Care in a safe deposit box.

i Although you are not required to update your Durable Power of Attorney for Health Care, you may want to review it periodically.

Commonly Used Life-Support Measures Are Listed on the Back Inside Page

DURABLE POWER OF ATTORNEY FOR HEALTH CARE
(RHODE ISLAND HEALTH CARE ADVANCE DIRECTIVE)

I, ____,
(Insert your name and address)
am at least eighteen (18) years old, a resident of the State of Rhode Island, and understand this document allows me to name another person (called the health care agent) to make health care decisions for me if I can no longer make decisions for myself and I cannot inform my health care providers and agent about my wishes for medical treatment.

PART I: APPOINTMENT OF HEALTH CARE AGENT
THIS IS WHO I WANT TO MAKE HEALTH CARE DECISIONS FOR ME IF I CAN NO LONGER MAKE DECISIONS

Note: You may not appoint the following individuals as an agent:

(1) your treating health care provider, such as a doctor, nurse, hospital, or nursing home,
(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*.*

When I am no longer able to make decisions for myself, I name and appoint ____ to make health care decisions for me. This person is called my health care agent.

Telephone number of my health care agent: ____
Address of my health care agent: ____
____

You should discuss this health care directive with your agent and give your agent a copy.

(OPTIONAL)
APPOINTMENT OF ALTERNATE HEALTH CARE AGENTS:

You are not required to name alternative health care agents. An alternative health care agent will be able to make the same health care decisions as the health care agent named above, if the health care agent is unable or ineligible to make health care decisions for you. For example, if you name your spouse as your health care agent and your marriage is dissolved, then your former spouse is ineligible to be your health care agent.

When I am no longer able to make decisions for myself and my health care agent is not available, not able, loses the mental capacity to make health care decisions for me, becomes ineligible to act as my agent, is not willing to make health care decisions for me, or I revoke the person appointed as my agent to make health care decisions for me, I name and appoint the following persons as my agent to make health care decision for me as authorized by this document, in the order listed below:

_____ **My Initials**

My **First Alternative Health Care Agent**: ____
Telephone number of my first alternative health care agent: ______________________________
Address of my first alternative health care agent: ______________________________________
____

My **Second Alternative Health Care Agent**: ____
Telephone number of my second alternative health care agent: ___________________________
Address of my second alternative health care agent: ____________________________________
____

My health care agent is automatically given the powers I would have to make health care decisions for me if I were able to make such decisions. Some typical powers for a health care agent are listed below in (A) through (H). My health care agent must convey my wishes for medical treatment contained in this document or any other instructions I have given to my agent. If I have not given health care instructions, then my agent must act in my best interest. A court can take away the power of an agent to make health care decisions for you if your agent:

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

Whenever I can no longer make decisions about my medical treatment, my health care agent has the power to:

(A) Make any health care decision for me. This includes the power to give, refuse, or withdraw consent to any care, treatments, services, tests, or procedures. This includes deciding whether to stop or not start health care that is keeping me or might keep me alive, and deciding about mental health treatment.
(B) Advocate for pain management for me.
(C) Choose my health care providers, including hospitals, physicians, and hospice.
(D) Choose where I live and receive health care which may include residential care, assisted living, a nursing home, a hospice, and a hospital.
(E) Review my medical records and disclose my health care information, as needed.
(F) Sign releases or other documents concerning my medical treatment.
(G) Sign waivers or releases from liability for hospitals or physicians.
(H) Make decisions concerning participation in research.

If I DO NOT want my health care agent to have a power listed above in (A) through (H) OR if I want to LIMIT an power in (A) through (H), I must say that here:

____
____
____
____

_____ My Initials

PART II: HEALTH CARE INSTRUCTIONS

THIS IS WHAT I WANT AND DO NOT WANT FOR MY HEALTH CARE

Many medical treatments may be used to try to improve my medical condition in certain circumstances or to prolong my life in other circumstances. Many medical treatments can be started and then stopped if they do not help. Examples include artificial breathing by a machine connected to a tube in the lungs, artificial feeding or fluids through tubes, attempts to start the heart, surgeries, dialysis, antibiotics, and blood transfusions. The back inside page has more information about life-support measures.

OPTIONAL -FOR DISCUSSION PURPOSES

A discussion of these questions with your health care agent may help him or her make health care decisions for you which reflect your values when you cannot make those decisions.

These are my views which may help my agent make health care decisions:

1. Do you think your life should be preserved for as long as possible? Why or why not?

____

____

____

2. Would you want your pain managed, even if it makes you less alert or shortens your life?

____

____

____

3. Do your religious beliefs affect the way you feel about death? Would you prefer to be buried or cremated?

____

____

____

4. Should financial considerations be important when making a decision about medical care?

____

____

____

5. Have you talked with your agent, alternative agent, family and friends about these issues?

____

____

____

_____ **My Initials**

Here are my desires about my health care to guide my agent and health care providers.

1. If I am close to death and life support would only prolong my dying:

INITIAL ONLY ONE:
______ I want to receive a feeding tube.
______ I DO NOT WANT a feeding tube.

INITIAL ONLY ONE:
______ I want all life support that may apply.
______ I want NO life support.

2. If I am unconscious and it is very unlikely that I will ever become conscious again:

INITIAL ONLY ONE:
______ I want to receive a feeding tube.
______ I DO NOT WANT a feeding tube.

INITIAL ONLY ONE:
______ I want all other life support that may apply.
______ I want NO life support.

3. If I have a progressive illness that will be fatal and is in an advanced stage, and I am consistently and permanently unable to communicate by any means, swallow food and water safely, care for myself and recognize my family and other people, and it is very unlikely that my condition will substantially improve:

INITIAL ONLY ONE:
______ I want to receive a feeding tube.
______ I DO NOT WANT a feeding tube.

INITIAL ONLY ONE:
______ I want all life support that may apply.
______ I want NO life support.

Additional statement of desires, special provisions, and limitations regarding health care decisions *(More space is available on page 8)*:

____

____

ORGAN DONATION

_____ In the event of my death, I request that my agent inform my family or next of kin of my desire to be an organ and tissue donor for **transplant**. *(Initial if applicable)*

_____ In the event of my death, I request that my agent inform my family or next of kin of my desire to be an organ and tissue donor for **research**. *(Initial if applicable)*

_____ My Initials

RELIGIOUS AND SPIRITUAL REQUESTS

Do you want your Rabbi, Priest, Clergy, Minister, Imam, Monk, or other spiritual advisor contacted if you become sick?

INITIAL ONLY ONE:
______ Yes ______ No

Name of Rabbi, Priest, Clergy, Minister, Imam, Monk, or other spiritual advisor:
____

Address:____

Phone Number: ____

DURATION

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

I do not want this durable power of attorney for health care to exist until revoked. I want this durable power of attorney for health care to expire on ___________________________________

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

REVOCATION

I can revoke this Durable Power of Attorney for Health Care at any time and for any reason either in writing or orally. If I change my agent or alternative agents or make any other changes, I need to complete a new Durable Power of Attorney for Health Care with those changes.

PART III: MAKING THE DOCUMENT LEGAL

I revoke any prior designations, advance directives, or durable power of attorney for health care.

Date and Signature of Principal

I am thinking clearly, I agree with everything that is written in this document, and I have made this document willingly.

____
Signature Date signed:

_____ My Initials

DATE AND SIGNATURES OF TWO QUALIFIED WITNESSES OR ONE NOTARY PUBLIC

Two qualified witnesses or one notary public must sign the durable power of attorney for health care form at the same time the principal signs the document. The witnesses must be adults and must not be any of the following:

(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, or
(5) an employee of an operator of a community care facility.

I declare under the 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 for health care 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, or an employee of an operator of a community care facility.

OPTION ONE:

Signature: ______________________________
Print Name: ______________________________
Residence Address: ______________________________
Date: ______________________________

Signature: ______________________________
Print Name: ______________________________
Residence Address: ______________________________
Date: ______________________________

--OR--

OPTION TWO:

Signature of Notary Public: ______________________________
Print Name: ______________________________
Commission Expires: ______________________________
Business Address: ______________________________
Date: ______________________________

TWO QUALIFIED WITNESSES OR ONE NOTARY PUBLIC DECLARATION

At least one of the qualified witnesses or the notary public must make this additional 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: ____

PART IV: DISTRIBUTING THE DOCUMENT

You are not required to give anyone your Durable Power of Attorney for Health Care, but if it cannot be found at the time you need it, it cannot help you. For example, you are unable to participate in making health care decisions and your Durable Power of Attorney for Health Care is a safe deposit box, the agent, physician and other health care providers will not have access to it and they will not be able to respect your medical treatment wishes. You may want to give a copy of your Durable Power of Attorney for Health Care to some or all of the persons listed below so that it can be available when you need it.

(Name) **(Address)** **(Phone)**

q Health Care Agent

____

q First Alternative Health Care Agent

____

q Second Alternative Health Care Agent

____

q Physician

____

q Family

____

q Lawyer

____

q Others

____

ADDITIONAL SPACE FOR INFORMATION

_____ **My Initials**

COMMONLY USED LIFE-SUPPORT MEASURES

Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart.

When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life-saving. But the success rate is extremely low for people who are at the end of a terminal disease process. Critically ill patients who receive CPR have a small chance of recovering or leaving the hospital.

Rhode Islanders with a terminal condition who do not want rescue/ambulance service/emergency medical services personnel to perform CPR may join COMFORT ONE. Rescue/ambulance/emergency workers will provide comfort measures but will not perform CPR or any resuscitation. To join COMFORT ONE, speak to your physician. ONLY your physician can enroll you in the COMFORT ONE PROGRAM. Your physician writes a medical order directing rescue/ambulances service/emergency personnel not to start CPR which is filed with the Rhode Island Department of Health.

Mechanical Ventilation

Mechanical ventilation is used to help or replace how the lungs work. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure happens due to injuries to the upper spinal cord or a progressive neurological disease.

Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important to them. For the dying patient, however, mechanical ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen, but it cannot improve the underlying condition.

When discussing end-of-life wishes, make clear to loved ones and your physician whether you would want mechanical ventilation if you would never regain the ability to breathe on your own or return to a quality of life acceptable to you.

Artificial Nutrition and Hydration

Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluid through a tube placed directly into the stomach, the upper intestine, or a vein. Artificial nutrition and hydration can save lives when used until the body heals.

Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. Sometimes long-term use of tube feeding frequently is given to people with irreversible and end-stage conditions which will not reverse the course of the disease itself or improve the quality of life. Some health care facilities and physicians may not agree with stopping or withdrawing tube feeding. You may want to talk with your loved ones and physician about your wishes for artificial nutrition and hydration in your Durable Power of Attorney for Health Care.

More copies of this form are available at: www.riag.state.ri.us

Poder legal por tiempo indefinido para cuidados de salud en Rhode Island

INSTRUCCIONES ANTICIPADAS PARA CUIDADOS DE SALUD

"LA VIRTUD DE ESTAR PREPARADO"

INTRODUCCIÓN

SUS DERECHOS

Los adultos tienen el derecho fundamental de controlar las decisiones relacionadas con el cuidado de su propia salud. Usted tiene derecho a tomar sus propias decisiones médicas y de cuidado de salud mientras esté en condiciones de dar su pleno consentimiento. No puede aplicársele ningún tratamiento si usted no está de acuerdo. Si tiene una enfermedad terminal, usted decide la administración o interrupción de un tratamiento determinado para mantenerlo con vida.

¿Qué es un poder legal por tiempo indefinido para cuidados de salud?

Este *Poder legal por tiempo indefinido para cuidados de salud* (Durable Power of Attorney for Health Care, DPAHC) le permite designar a una persona para que tome decisiones sobre cuidados de salud en su nombre cuando usted no pueda participar activamente en tomar decisiones. A la persona designada se le llama apoderado. El apoderado debe actuar según los deseos de usted, tal como los describe este documento o tal como se los conozca de alguna otra manera. El apoderado debe actuar teniendo el mejor interés del titular en mente. Su apoderado actúa en lugar de usted y puede tomar cualquier decisión sobre cuidados de salud que usted tenga derecho.

Lea con cuidado este *Poder legal por tiempo indefinido para cuidados de salud*. Cumpla con las indicaciones de la sección sobre testigos, tal como se le pide. Para que su voluntad se cumpla, este *Poder legal* debe ser válido.

RECUERDE QUE

- usted debe haber cumplido por lo menos 18 años de edad.
- debe ser residente del Estado de Rhode Island.
- debe seguir las instrucciones de este *Poder legal por tiempo indefinido para cuidados de salud.*
- debe firmar el documento de manera voluntaria.
- este *Poder legal* debe ser firmado frente a testigos.
- no es obligatorio utilizar ningún formulario específico, pero si utiliza éste, será aceptado como *Poder legal* por los proveedores de cuidados de salud.
- entregue copias del documento a su apoderado, su apoderado alterno, sus médicos, al hospital y a sus familiares.
- no guarde su *Poder legal* en una caja fuerte.
- aunque usted no está obligado a actualizar su *Poder legal a tiempo indefinido para cuidados de salud*, le conviene revisarlo periódicamente.

Las medidas más comunes para el sostenimiento artificial de vida están detalladas en el interior de la contratapa

PODER LEGAL POR TIEMPO INDEFINIDO PARA CUIDADOS DE SALUD (INSTRUCCIONES ANTICIPADAS PARA CUIDADOS DE SALUD DE RHODE ISLAND)

Yo, ____,

(Escriba su nombre completo y dirección postal)

tengo dieciocho (18) años o más de edad, soy residente del estado de Rhode Island y entiendo que este documento me permite designar a una persona (llamada apoderado para cuidados de salud, o simplemente apoderado) para que tome decisiones en mi nombre, si no puedo tomarlas y/o no puedo manifestar mis deseos sobre tratamientos médicos a las personas que me están atendiendo en el centro de salud.

PARTE I: NOMBRAMIENTO DE UN APODERADO PARA CUIDADOS DE SALUD PARA QUE TOME DECISIONES SOBRE CUIDADOS DE SALUD EN MI NOMBRE, SI YO NO PUEDO TOMARLAS

*Nota: **NO** puede designar como apoderado a las siguientes personas:*

1. ***su proveedor de cuidados de salud, como por ejemplo, su médico, enfermera, hospital u hogar para ancianos discapacitados;***
2. ***un empleado de su proveedor de cuidados de salud, que no sea pariente suyo;***
3. ***el encargado de un centro de salud comunitario; o***
4. ***un empleado del encargado de un centro de salud comunitario, que no sea pariente suyo.***

Cuando no pueda tomar decisiones por mi mismo, nombro y otorgo autorización a ____ para que tome decisiones sobre cuidados de salud en mi nombre. Esta persona será mi apoderado.

Número de teléfono de mi apoderado: ____

Dirección postal de mi apoderado: ____

____

Converse con su apoderado sobre estas instrucciones y entréguele una copia.

(OPCIONAL)
NOMBRAMIENTO DE APODERADOS ALTERNOS

Usted no está obligado a nombrar apoderados alternos para cuidados de salud. Un apoderado alterno está facultado para tomar las mismas decisiones sobre cuidados de salud que el apoderado designado líneas arriba, en caso que este último no sea capaz, o no esté calificado, para tomar decisiones por usted. Por ejemplo, si nombra a su cónyuge como apoderado y luego se divorcia, entonces su cónyuge queda descalificado para actuar como su apoderado.

Cuando yo no sea capaz de tomar mis propias decisiones y, mi apoderado no esté disponible, o no sea capaz, o haya perdido la capacidad mental para tomar decisiones en mi nombre, o quede descalificado para actuar como mi apoderado, o no desee tomar decisiones sobre cuidados de salud en mi nombre, o yo haya revocado su nombramiento, entonces nombro y otorgo autorización a las siguientes personas como apoderados míos para que tomen decisiones sobre el cuidado de mi salud, tal y como se autoriza en el

_____ Mis iniciales

presente documento y en el orden en que aparecen:

Mi **primer apoderado alterno**: ____
Teléfono de mi primer apoderado alterno: ________________________________
Dirección postal de mi primer apoderado alterno: ___________________________
____

Mi **segundo apoderado alterno**: ____
Teléfono de mi segundo apoderado alterno: _______________________________
Dirección postal de mi segundo apoderado alterno: __________________________
____

Automáticamente, mi apoderado tiene las mismas facultades que yo para tomar decisiones sobre el cuidado de mi salud, si es que yo no pudiera tomarlas. Algunas facultades típicas de un apoderado para cuidados de salud están detalladas más abajo, en los acápites desde (A) hasta (H). Mi apoderado debe dar a conocer mis deseos sobre tratamientos médicos contenidos en este documento, o cualquiera otras instrucciones que yo haya comunicado a mi apoderado. Si no he preparado instrucciones para el cuidado de mi salud, entonces mi apoderado actuará según mi mejor conveniencia. Un tribunal puede revocar las facultades del apoderado, en caso que:

(1) autorice algo ilegal;
(2) actúe de manera contraria a sus deseos conocidos; o
(3) tome cualquier acción evidentemente contraria a su mejor conveniencia, cuando sus deseos no se conocen.

Desde el momento en que yo ya no pueda tomar decisiones sobre mis tratamientos médicos, mi apoderado tendrá facultad para:

(A) tomar cualquier decisión sobre cuidados de salud en mi nombre, que incluye las facultades para aceptar, rehusar, o interrumpir, cualquier tipo de cuidado, tratamiento, servicio, prueba, o procedimiento. También incluye la decisión de interrumpir, o dejar de administrar, el cuidado de salud que me mantiene, o podría mantenerme, con vida y la decisión respecto a tratamientos de salud mental.
(B) interceder por mí con respecto al tratamiento del dolor.
(C) escoger a mis proveedores de cuidados de salud, lo que incluye hospitales, médicos y establecimientos para cuidado terminal.
(D) determinar dónde voy a vivir y recibir cuidados de salud, lo que puede incluir centros residenciales de cuidado, hogares para el cuidado de ancianos discapacitados, establecimientos para cuidado terminal u hospitales.
(E) cuando sea necesario, revisar mi historia clínica y revelar la información sobre el cuidado de mi salud.
(F) firmar desestimientos u otros documentos relativos a mi tratamiento médico.
(G) Firmar documentos con cláusulas de renuncia a reclamos por responsabilidad civil a hospitales, o médicos.
(H) tomar decisiones sobre mi participación en estudios de investigación.

Si NO DESEO que mi apoderado tenga alguna de las facultades mencionadas de (A) a (H), O si DESEO restringir alguna de las facultades mencionadas de (A) a (H), debo ponerlo por escrito a continuación:

_____ Mis iniciales

PARTE II: INSTRUCCIONES PARA CUIDADOS DE SALUD

LO QUE DESEO Y NO DESEO PARA EL CUIDADO DE MI SALUD

Se puede utilizar muchos tratamientos médicos para tratar de mejorar mi estado de salud en determinadas circunstancias, o para prolongar mi vida, en otras. Se puede iniciar y luego interrumpir, muchos tratamientos médicos si no dan resultado. Ejemplo de lo anterior son respiración artificial, alimentación artificial, administración de líquidos a través de tubos, intentos para que el corazón vuelva a latir, cirugías, diálisis, antibióticos y transfusiones de sangre. En el interior de la contratapa hay más información sobre sostenimiento artificial de la vida.

OPCIONAL, PARA FINES DE DISCUSIÓN

Si conversa sobre estas preguntas con su apoderado, le ayudará a él/ella a tomar decisiones sobre cuidados de salud en su nombre que reflejen sus valores, cuando usted no pueda tomarlas.

Éstos son mis puntos de vista, que ayudarán a mi apoderado a tomar decisiones sobre el cuidado de mi salud:

1. ¿Piensa usted que se le debiera mantener con vida tanto como sea posible? ¿Por qué si, o por qué no?

____

____

____

2. ¿Desea usted que se le controle el dolor aun si eso significa pérdida de agilidad mental o si se le acorta el tiempo de supervivencia?

____

____

____

3. ¿Si usted tiene una condición, un mal, o enfermedad letal, usted quisiera que se le provea su cuidado de salud en su hogar o en un centro de asistencia médica, por ejemplo un asilo para ancianos o un hospital?

____

____

____

4. ¿Sus creencias religiosas tienen que ver con lo que usted piensa sobre la muerte? ¿Prefiere usted ser enterrado, o cremado?

____

____

____

5. ¿Es importante tener en cuenta el costo, o aspecto financiero, cuando se va a tomar una decisión sobre cuidados de salud?

____

____

____

_____ Mis iniciales

6. ¿Ha conversado usted sobre estos asuntos con su apoderado, apoderado alterno, familiares y amigos?
____

A continuación, indico mis deseos sobre cuidados de salud a fin de orientar a mi apoderado y a mis proveedores de cuidados de salud.

1. Si voy a morir y el sostenimiento artificial de vida solo prolonga mi agonía:

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Deseo alimentarme a través de un tubo.
______ NO DESEO alimentarme a través de un tubo.

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Deseo que se me mantenga con vida artificialmente.
______ NO DESEO que se me mantenga con vida artificialmente.

2. Si estoy inconsciente y es poco probable que recobre la conciencia:

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Deseo alimentarme a través de un tubo.
______ NO DESEO alimentarme a través de un tubo.

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Deseo que se me mantenga con vida artificialmente.
______ NO DESEO que se me mantenga con vida artificialmente.

3. Si tengo una enfermedad fatal que se encuentra en estado avanzado y soy incapaz de comunicarme por ningún medio de manera permanente y no puedo ingerir alimentos o agua de manera segura y no puedo atender mis necesidades y no reconozco a mis familiares y a otras personas y es poco probable que mi estado de salud mejore:

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Deseo alimentarme a través de un tubo.
______ NO DESEO alimentarme a través de un tubo.

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Deseo que se me mantenga con vida artificialmente.
______ NO DESEO que se me mantenga con vida artificialmente.

Declaraciones adicionales de deseos, cláusulas especiales y restricciones respecto a decisiones sobre cuidados de salud *(espacio adicional disponible en la página 8)*:
____
____

DONACIÓN DE ORGANOS

_____ En caso que yo muera, deseo que mi apoderado comunique a mi familia, o pariente más cercano, mi voluntad de donar mis órganos y tejidos para **transplantes**. *(En caso afirmativo, escriba sus iniciales)*

_____ Mis iniciales

_____ En caso que yo muera, deseo que mi apoderado le comunique a mi familia, o pariente más cercano, mi voluntad de donar mis órganos y tejidos para fines de **investigación**. *(En caso afirmativo, escriba sus iniciales)*

REQUERIMIENTOS RELIGIOSOS Y ESPIRITUALES

¿Si usted se enferma, desea que se le informe a su rabino, sacerdote, clérigo, ministro, imán, monje, u otro consejero espiritual,?

ESCRIBA SUS INICIALES SOLAMENTE EN UNA DE LAS RESPUESTAS:
______ Sí ______ No

Nombre del rabino, sacerdote, clérigo, ministro, imán, monje, u otro consejero espiritual:
____

Dirección postal: ____

Teléfono: ____

PARTE III: PARA DARLE VALOR LEGAL A ESTE DOCUMENTO

Anulo cualquier nombramiento anterior, o instrucciones anticipadas previas, o *Poder legal por tiempo indefinido para cuidados de salud* anterior.

VIGENCIA

Si usted no especifica un plazo determinado en el espacio disponible a continuación, este poder legal estará vigente hasta que sea revocado.

No deseo que este poder legal por tiempo indefinido esté vigente hasta su revocatoria. Deseo que este poder legal por tiempo indefinido para cuidados de salud venza el ____________________
(Escriba en este espacio SOLAMENTE si desea que las facultades de su apoderado venzan en una fecha específica)

REVOCATORIA/CANCELACIÓN

Puedo revocar/cancelar este *Poder legal* en cualquier momento y por cualquier razón, ya sea por escrito, o verbalmente. Si sustituyo a mi apoderado, o apoderados alternos, o realizo cualquier otro cambio, debo preparar un nuevo *Poder legal* que incluya esas modificaciones.

Fecha y firma del titular

Tengo la mente lúcida, estoy de acuerdo con lo escrito en este documento y lo he preparado de manera voluntaria.

____
Firma Fecha:

_____ Mis iniciales

FECHA Y FIRMA DE DOS TESTIGOS CALIFICADOS, O UN NOTARIO PÚBLICO

Dos testigos calificados, o un notario público, deben firmar el *Poder legal por tiempo indefinido para cuidados de salud*, en el mismo momento en que el titular firma. Los testigos deben ser adultos y NO puede ser ninguno de los siguientes:

(1) la persona que usted nombró como su apoderado, o apoderado alterno,
(2) proveedor de cuidados de salud,
(3) empleado de un proveedor de cuidados de salud,
(4) encargado de un centro de salud comunitario, o
(5) empleado del encargado de un centro de salud comunitario.

Declaro, bajo pena de perjurio, que reconozco personalmente como titular a la persona que ha firmado o aceptado este documento, que la persona titular ha firmado o aceptado este *Poder legal a tiempo indefinido para cuidados de salud* en mi presencia, que la persona titular parece encontrarse lúcida y que no está siendo coaccionada, engañada, o influída indebidamente, que no soy la persona nombrada como apoderado en este documento y que no soy un proveedor de cuidados de salud, ni empleado de un proveedor de cuidados, ni encargado de un centro de cuidados de la comunidad, ni empleado de un encargado de un centro de cuidados de la comunidad.

PRIMERA OPCIÓN:

Firma: ____
Nombre: ____
Dirección donde reside: _____________________________
Fecha: ____

Firma: ____
Nombre: ____
Dirección donde reside: _____________________________
Fecha: ____

---**O, EN CAMBIO**-----------------------------

SEGUNDA OPCIÓN:

Firma del Notario público: ___________________________
Nombre: ____
Su nombramiento vence: _____________________________
Dirección de trabajo: ________________________________
Fecha: ____

DECLARACIÓN DE DOS TESTIGOS CALIFICADOS, O DE UN NOTARIO PÚBLICO

Por lo menos, uno de los testigos calificados, o un Notario público, debe firmar esta declaración adicional:

Declaro, bajo pena de perjurio, que no tengo ninguna relación de parentesco por sangre,

_____ Mis iniciales

matrimonio, o adopción con la persona titular y que hasta donde alcanza mi conocimiento, no tengo derecho a parte alguna de su herencia luego de su muerte por el hecho de haber sido, o no, incluido en su testamento vigente, o por mandato de la ley.

Firma: ____
Nombre: ____

Firma: ____
Nombre: ____

PARTE IV: DISTRIBUCIÓN DEL DOCUMENTO

Usted no está obligado a entregar copia de su Poder legal por tiempo indefinido para cuidados de salud *a ninguna persona, pero si el documento no es ubicado en el momento oportuno, no será de ninguna utilidad para usted. Por ejemplo, puede ser que usted no sea capaz de participar en la toma de decisiones y su* Poder legal por tiempo indefinido para cuidados de salud *se encuentre guardado en una caja fuerte. Su apoderado, su médico, u otros proveedores de cuidados de salud, no tendrán acceso al documento y no podrán respetar sus deseos sobre tratamientos médicos. Es conveniente que entregue una copia de su* Poder legal por tiempo indefinido para cuidados de salud *a algunas de las personas, o a todas las personas, mencionadas a continuación, a fin de que el documento se encuentre disponible cuando sea necesario.*

(Nombre) **(Dirección postal)** **(Teléfono)**

☐ Apoderado para cuidados de salud

____

☐ Primer apoderado alterno para cuidados de salud

____

☐ Segundo apoderado alterno para cuidados de salud

____

☐ Médico

____

☐ Familiares

____

☐ Abogado

____

☐ Otros

____

_____ Mis iniciales

ESPACIO ADICIONAL PARA MAYOR INFORMACIÓN

_____ Mis iniciales

MEDIDAS MÁS COMUNES PARA EL SOSTENIMIENTO ARTIFICIAL DE VIDA

Resucitación cardiopulmonar (Cardiopulmonary Resuscitation, CPR)

La CPR consiste de una serie de tratamientos que se administran cuando el corazón de una persona deja de latir, o la persona deja de respirar. La CPR se utiliza para tratar de recuperar el funcionamiento del corazón y la respiración. Puede consistir solamente en dar respiración boca a boca, o ejercer presión en el pecho para imitar el funcionamiento del corazón y permitir la circulación de la sangre. Con frecuencia, también se utiliza choque eléctrico y drogas para estimular el corazón.

La CPR salva vidas cuando se utiliza de inmediato en respuesta a un suceso repentino, como un ataque al corazón o ahogamiento, pero, el porcentaje de éxito es bajo para personas en la última fase de una enfermedad terminal. Los pacientes en estado crítico que reciben CPR, tienen pocas probabilidades de recuperarse, o de dejar el hospital.

Los residentes de Rhode Island con enfermedad terminal que no desean que el personal que presta servicios médicos de emergencia, o de ambulancia, o de rescate, le administre CPR, pueden inscribirse en COMFORT ONE. El personal que presta servicios médicos de emergencia, o de ambulancia, o de rescate, proporcionará alivio y bienestar, pero no administrará CPR, u otro medio de resucitación. Para inscribirse en COMFORT ONE hable con su médico, SOLAMENTE su médico puede autorizar la inscripción en el programa COMFORT ONE. Su médico debe redactar una orden señalando al personal que presta servicios médicos de emergencia, o de ambulancia, o de rescate, que no administre CPR. Esta orden se archiva en el Departamento de salud de Rhode Island.

Ventilación mecánica

Se utiliza ventilación mecánica para asistir, o reemplazar, el trabajo de los pulmones. Se forza el aire a los pulmones con una máquina llamada ventilador, o respirador. El ventilador se conecta a un tubo insertado en la nariz o boca que llega hasta la tráquea. Con frecuencia, la ventilación mecánica se utiliza para ayudar a una persona con un problema de corta duración, o se administra por periodos más prolongados cuando se presentan fallas irreversibles de respiración debido a daños en la parte superior de la espina dorsal, o por enfermedades neurológicas avanzadas.

Algunas personas que utilizan ventilación mecánica por tiempo prolongado pueden disfrutar y mantener un nivel de calidad de vida satisfactorio. Sin embargo, la ventilación mecánica en pacientes a punto de morir solamente prolonga la agonía hasta que falla algún otro sistema vital. La ventilación mecánica suministra oxígeno, pero no mejora el problema de fondo.

Cuando converse con sus seres queridos y con su médico sobre sus deseos en la fase final de su vida, deje claramente establecido si quiere ventilación mecánica en caso que no pueda recuperar la facultad de respirar por sí mismo, o en todo caso, para mantener una calidad de vida aceptable.

Alimentación e hidratación artificial

La alimentación e hidratación artificial (o alimentación a través de un tubo) complementa, o reemplaza, los alimentos y el agua que se ingiere convencionalmente al proporcionarle una mezcla químicamente balanceada de sustancias nutritivas y líquidos a través de un tubo insertado en el estómago, en el intestino delgado, o en una vena. La alimentación e hidratación artificial salva vidas cuando se administra mientras se recupera la salud.

La alimentación e hidratación artificial por periodos prolongados se administra a personas con enfermedades intestinales severas que limitan su capacidad de digerir alimentos, por consiguiente, les ayuda a disfrutar de calidad de vida satisfactoria. En algunas ocasiones, la alimentación artificial por tiempo prolongado se administra a personas con enfermedades irreversibles y terminales, procedimiento que no cambia el curso de la enfermedad, ni mejora la calidad de vida. Algunos médicos y centros de cuidados de salud no están de acuerdo en interrumpir, o dejar de administrar, alimentación artificial. Usted debe conversar con sus seres queridos y con su médico respecto de sus deseos de recibir alimentación e hidratación artificial, para incluirla en su *Poder legal por tiempo indefinido para cuidados de salud.*

_____ Mis iniciales

Se encuentra copias adicionales de este formulario en: www.riag.state.ri.us or www.HEALTH.RI.Gov
o del Departamento de Asuntos de Ancianos de Rhode Island

HEALTH CARE PROXY

TO: My family, physicians and all
those concerned with my care

I, _____________________(Your name), presently residing at _________________Street, ___________________ (City or Town), MA. _______ (zipcode), and being an adult of sound mind, pursuant to Massachusetts General Laws, Chapter 201D, hereby appoint and authorize ___________________________ (Name of your healthcare agent), presently residing at _______________________________ (Health Agent's Address), telephone number:__________ , as my agent to act for me and in my name to make and communicate any and all decisions about or relating to my receipt or refusal to accept medical treatment, hospitalization, health care or personal care, in any situation in which, as the result of illness, disease, mental deterioration or injury, I am incapable of making or communicating a decision with respect to my treatment or care. This authorization includes the right to refuse and direct the withdrawal of medical treatment which would prolong my life, and to communicate health care decisions to all persons including without limitation my physicians, health care providers and family.

NOTE: In the space provided below, insert any specific desires, special provisions or limitations which you desire:

I further delegate to my agent the power and authority to select, employ and discharge health care personnel, such as physicians, nurses, therapists, hospice care and home health care providers, and other medical professionals; to admit or discharge me (including transfer from another facility) from any hospital, hospice, nursing home, adult home or other medical care facility; and to apply for public benefits to defray the cost of health care, and to contract in my name and on my behalf for all health care services, including without limitation medical, nursing and hospital care, as my agent may deem appropriate. I confirm that I shall be and remain personally liable for the payment of all such care and services to the same extent as if I had personally contracted therefor.

{**OPTIONAL**} I authorize my agent to donate all or any part of my body for transplantation, therapy, advancement of medical or dental science, research, or other medical, educational or scientific purpose, or to otherwise direct the disposition of my remains.

I further authorize my agent to request, receive and review any information regarding my physical or mental health, including without limitation medical and hospital records; to execute on my behalf any releases or other documents that may be required in order to obtain this information; and to consent to the disclosure of this information. I authorize my agent to execute on my behalf any documents necessary or desirable to implement the health care decisions that my agent is authorized to make pursuant to this document, including without limitation all documents pertaining to a refusal to permit medical treatment, or authorizing the leaving of a medical facility against medical advice, or any waivers or releases from liability required by a physician or health care provider.

I reserve the power to revoke this document at any time by communicating my intent to revoke in any manner in which I am able to communicate.

The authority of my agent shall become effective when I can no longer make or communicate my own medical decisions. The determination of whether I can make or communicate my own medical decisions is to be made by my attending physician. I have read the foregoing notice concerning the legal consequences of my executing this document. I have discussed my wishes with, and have carefully selected, my agent.

IN WITNESS WHEREOF, I have executed this instrument, as my free and voluntary act and deed, this ________ day of ________, 20___.

____
YOUR NAME

WITNESS:

We, (Witness #1) ______________________and (Witness #2) ______________________, each hereby attest and declare under penalty of perjury under the laws of the Commonwealth of Massachusetts that: (1) the foregoing instrument was personally signed by _____________________ (Your name) in my presence, and thereupon I, at his/her request and in his/her presence and in the presence of the other witnesses, have hereunto subscribed my name as a witness; (2) I did not sign the above signature of _____________________ (Your name) for or at his/her direction; (3) I personally know _____________________ (Your name) and believe him/her to be of sound mind and under no constraint, duress, fraud or undue influence; (4) I am not related to _____________________ (Your name) by blood, marriage or adoption; (5) I am not entitled (to the best of my knowledge and belief) to any portion of the estate of _____________________ (Your name) upon his/her death under any will or codicil or by operation of law; (6) I do not have any present or inchoate claim against any portion of the estate of _____________________ (Your name); (7) I do not have any financial responsibility for the medical care of _____________________ (Your name); (8) I am not a physician or an employee of any physician, and I am not an operator or employee of, or patient in, any hospital, health care provider, residential care facility, community care facility or similar institution; (9) I am not a person named as agent in this instrument; and (10) I am at least 18 years of age.

Dated: __________, 20___

____

residing at

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residing at

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INSTRUCTIONS
To Living Will

A living will is a written document which directs your physician to withhold or stop life-sustaining medical procedures if you develop a terminal condition and can't state your wishes at the time a decision about those kinds of procedures must be made.

Rhode Island law suggests a form of living will but does not require its exclusive use. If you decide to sign a living will, you may use the form supplied with these instructions or make your own living will form. If you use this form, please read and follow these instructions carefully.

1. Print your name in the first line of the form.

2. Place a check mark in the third paragraph to indicate whether you want artificially-administered nutrition and hydration (food and water) to be stopped or withheld like any other life-sustaining treatment. Remember, if you do not want artificial nutrition and hydration, your living will must say so.

3. Complete the day, month and year that you sign at the bottom of this form.

4. Sign your name on the signature line (or if you are unable to do so, have someone do it for you) before two (2) witnesses who know you and are at least 18 years old.

5. Print your address on the address line.

6. Have the two (2) witnesses sign their names and print their addresses where indicated below your signature. The witnesses may not be related to you by blood or marriage.

7. Give a signed copy of your living will to your physician for your medical records.

   Remember, you may revoke your living will at any time simply by telling your physician not to follow it.

NOTE: This information is provided to make you generally aware of Rhode Island law about living wills and is not intended as legal advice for your particular situation. For legal advice about living wills or your health care rights, you should consult with an attorney.

STATE OF RHODE ISLAND

CHAPTER 23-4.11

A declaration may, but need not, be in the following form:

RIGHTS OF THE TERMINALLY ILL ACT

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, so hereby declare:

If I should have an incurable or irreversible condition that will cause my death 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 _____________________, __________.

____
Signature of Declarant

____
Address

The Declarant is personally known to me and voluntarily signed this document in my presence. I am not related to the Declarant by blood or marriage.

____
Witness

____
Witness

____
Address

____
Address

LIVING WILL

TO: My family, physicians and all
those concerned with my care

I, presently residing at_________________,________, and being an adult of sound mind, make this declaration as a directive to be followed if for any reason I become unable to make or communicate decisions regarding my medical care.

I do not want medical treatment that will keep me alive if I am unconscious and there is no reasonable prospect that I will ever be conscious again (even if I am not going to die soon in my medical condition) or if I am near death from an illness or injury with no reasonable prospect of recovery. The procedures and treatment to be withheld and withdrawn include, without limitation, surgery, antibiotics, cardiac and pulmonary resuscitation, respiratory support, and artificially administered feeding and fluids. I direct that treatment be limited to measures to keep me comfortable and to relieve pain, even if such measures shorten my life.

[OPTIONAL] I wish to live out my last days at home rather than in a hospital, if it does not jeopardize the chance of my recovery to a meaningful and conscious life and does not impose an undue burden on my family.

[OPTIONAL] If, upon my death, any of my tissue or organs would be of value for transplantation, therapy, advancement of medical or dental science, research, or other medical, educational or scientific purpose, I freely give my permission to the donation of such tissue or organs.

These directions are the exercise of my legal right to refuse treatment. Therefore, I expect my family, physicians, health care facilities and all concerned with my care to regard themselves as legally and morally bound to act in accordance with my wishes, and in so doing to be free from any liability for having followed my directions.

IN WITNESS WHEREOF, I have executed this declaration, as my free and voluntary act and deed, this ____day of _________, 20__.

____

WITNESS:

We, the undersigned witnesses, each hereby attest and declare under penalty of perjury under the laws of the Commonwealth of Massachusetts that: (1) the foregoing instrument was personally signed by in my presence, and thereupon I, at his request and in his/her presence and in the presence of the other witnesses, have hereunto subscribed my name as a witness; (2) I did not sign the above signature of (YOUR NAME) for or at his/her direction; (3) I personally know (YOUR NAME) and believe him/her to be of sound mind and under no constraint, duress, fraud or undue influence; (4) I am not related to (YOUR NAME) by blood, marriage or adoption; (5) I am not entitled (to the best of my knowledge and belief) to any portion of the estate of (YOUR NAME) upon his/her death under any will or codicil of (YOUR NAME) or by operation of law; (6) I do not have any present or inchoate claim against any portion of the estate of (YOUR NAME); (7) I do not have any financial responsibility for the medical care of (YOUR NAME); (8) I am not a physician or an employee of any physician, and I am not an operator or employee of, or patient in, any hospital, health care provider, residential care facility, community care facility or similar institution; and (9) I am at least 18 years of age.

Dated: _________, 20__

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residing at

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TIPS FOR COMMUNICATING ACROSS LANGUAGE BARRIERS

Limited English Proficient (LEP) patients are faced with language barriers that undermine their ability to understand information given by healthcare providers as well as instructions on prescriptions and medication bottles, appointment slips, medical education brochures, doctor's directions, and consent forms. They experience more difficulty (than other patients) processing information necessary to care for themselves and others.

Tips to Identify a Patient's Preferred Language

- Ask the patient for their preferred spoken and written language.
- Display a poster of common languages spoken by patients; ask them to point to their language of preference.
- Post information relative to the availability of interpreter services.
- Make available and encourage patients to carry "I speak…." or "Language ID" cards.

(Note: Many phone interpreter companies provide language posters and cards at no charge.)

Tips to Document Patient Language Needs

- For all Limited English Proficient (LEP) patients, document preferred language in paper and/or electronic medical records.
- Post color stickers on the patient's chart to flag when an interpreter is needed. (e.g. Orange =Spanish, Yellow=Vietnamese, Green=Russian).

Tips to Assessing which Type of Interpreter to Use

- Telephone interpreter services are easily accessed and available for short conversations or unusual language requests.
- Face-to-face interpreters provide the best communication for sensitive, legal or long communications.
- Trained bilingual staff provide consistent patient interactions for a large number of patients.
- For reliable patient communication, avoid using minors and family members.

Tips to Overcome Language Barriers

- Use simple words; avoid jargon and acronyms.
- Limit/avoid technical language.
- Speak slowly (don't shout).
- Articulate words completely.
- Repeat important information.
- Provide educational material in the languages your patients read.
- Use pictures, demonstrations, video or audiotapes to increase understanding.
- Give information in small chunks and verify comprehension before going on.
- Always confirm patient's understanding of the information - patient's logic may be different from yours.

NON-VERBAL COMMUNICATION AND PATIENT CARE

Non-verbal communication is a subtle form of communication that takes place in the **initial three second**s after meeting someone for the first time and can continue through the entire interaction. Research indicates that non-verbal communication accounts for approximately **70%** of a communication episode. Non-verbal communication can impact the success of communication more acutely than the spoken word. Our culturally informed unconscious framework evaluates gestures, appearance, body language, the face, and how space is used. Yet, we are rarely aware of how persons from other cultures perceive our non-verbal communication or the subtle cues we have used to assess the person.

The following are case studies that provide examples of non-verbal miscommunication that can sabotage a patient-provider encounter. Broad cultural generalizations are used for illustrative purposes. They should not be mistaken for stereotypes. A stereotype and a generalization may appear similar, but they function very differently. A **stereotype** is an ending point; no attempt is made to learn whether the individual in question fits the statement. A **generalization** is a beginning point; it indicates common trends, but further information is needed to ascertain whether the statement is appropriate to a particular individual.

Generalizations can serve as a guide to be accompanied by individualized in-person assessment. As a rule, ask the patient, rather than assume you know the patient's needs and wants. If asked, patients will usually share their personal beliefs, practices and preferences related to prevention, diagnosis and treatment.

Eye Contact

Ellen was trying to teach her Navaho patient, Jim Nez, how to live with his newly diagnosed diabetes. She soon became extremely frustrated because she felt she was not getting through to him. He asked very few questions and never met her eyes. She reasoned from this that he was uninterested and therefore not listening to her.[1]

It is rude to meet and hold eye contact with an elder or someone in a position of authority such as health professionals in most Latino, Asian, American Indian and many Arab countries. It may be also considered a form of social aggression if a male insists on meeting and holding eye contact with a female.

Touch and Use of Space

A physician with a large medical group requested assistance encouraging young female patients to make and keep their first well woman appointment. The physician stated that this group had a high no-show rate and appointments did not go as smoothly as the physician would like.

Talk the patient through each exam so that the need for the physical contact is understood, prior to the initiation of the examination. Ease into the patients' personal space. If there are any concerns, ask before entering the three-foot zone. This will help ease the patient's level of discomfort and avoid any misinterpretation of physical contact. Additionally, physical contact between a male and female is strictly regulated in many cultures. An older female companion may be necessary during the visit.

Gestures

An Anglo patient named James Todd called out to Elena, a Filipino nurse: "Nurse, nurse." Elena came to Mr. Todd's door and politely asked, "May I help you?" Mr. Todd beckoned her to come closer by motioning with his right index finger. Elena remained where she was and responded in an angry voice, "What do you want?" Mr. Todd was confused. Why had Elena's manner suddenly changed?[2]

Gestures may have dramatically different meanings across cultures. It is best to think of gestures as a local dialect that is familiar only to insiders of the culture. Conservative use of hand or body gestures is recommended to avoid misunderstanding. In the case above, Elena took offense to Mr. Todd's innocent hand gesture. In the Philippines (and in Korea) the "come here" hand gesture is used to call animals.

Body Posture and Presentation

Carrie was surprised to see that Mr. Ramirez was dressed very elegantly for his doctor's visit. She was confused by his appearance because she knew that he was receiving services on a sliding fee scale. She thought the front office either made a mistake documenting his ability to pay for service, or that he falsely presented his income.

Many cultures prioritize respect for the family and demonstrate family respect in their manner of dress and presentation in public. Regardless of the economic resources that are available or the physical condition of the individual, going out in public involves creating an image that reflects positively on the family - the clothes are pressed, the hair is combed, and shoes are clean. A person's physical presentation is not an indicator of their economic situation.

Use of Voice

Dr. Moore had three patients waiting and was feeling rushed. He began asking health related questions of his Vietnamese patient Tanya. She looked tense, staring at the ground without volunteering much information. No matter how clearly he asked the question he couldn't get Tanya to take an active part in the visit.

The **use** of voice is perhaps one of the most difficult forms of non-verbal communication to change, as we rarely hear how we sound to others. If you speak too fast, you may be seen as not being interested in the patient. If you speak too loud, or too soft for the space involved, you may be perceived as domineering or lacking confidence. Expectations for the use of voice vary greatly between and within cultures, for male and female, and the young and old. *The best suggestion is to search for non-verbal cues to determine how your voice is affecting your patient.*

[1, 2] Galanti, G. (1997). *Caring for Patients from Different Cultures*. University of Pennsylvania Press.
Hall, E.T. (1985). *Hidden Differences: Studies in International Communication.* Hamburg: Gruner & Jahr.
Hall, E.T. (1990). *Understanding Cultural Differences.* Yarmouth, ME: Intercultural Press.

CULTURAL BACKGROUND
Information on Special Topics

Use of Alternative or Herbal Medications

- People who have lived in poverty, or come from places where medical treatment is difficult to get, will often come to the doctor only after trying many traditional or home treatments. Usually patients are very willing to share what has been used if asked in an accepting, non-judgmental way. This information is important for the accuracy of the clinical assessment.

- Many of these treatments are effective for treating the symptoms of illnesses. However, some patients may not be aware of the difference between treating symptoms and treating the disease.

- Some treatments and "medicines" that are considered "folk" medicine or "herbal" medications in the United States are part of standard medical care in other countries. Asking about the use of medicines that are "hard to find" or that are purchased "at special stores" may get you a more accurate understanding of what people are using than asking about "alternative," " traditional," "folk," or "herbal" medicine.

Pregnancy and Breastfeeding

- Preferred and acceptable ages for a first pregnancy vary from culture to culture. Latinos are more accepting of teen pregnancy; in fact it is quite common in many of the countries of origin. Russians tend to prefer to have children when they are older. It is important to understand the cultural context of any particular pregnancy. Determine the level of social support for the pregnant women, which may not be a function of age.

- Acceptance of pregnancy outside of marriage also varies from culture to culture and from family to family. In many Asian cultures there is often a profound stigma associated with pregnancy outside of marriage. However, it is important to avoid making assumptions about how welcome any pregnancy may be.

- Some Vietnamese and Latino women believe that colostrum is not good for a baby. An explanation from the doctor about why the milk changes can be the best tool to counter any negative traditional beliefs.

- The belief that breastfeeding works as a form of birth control is very strongly held by many new immigrants. It is important to explain to them that breastfeeding does not work as well for birth control if the mother gets plenty of good food, as they are more able to do here than in other parts of the world.

Weight

- In many poor countries, and among people who come from them, "chubby" children are viewed as healthy children because historically they have been better able to survive childhood diseases. Remind parents that sanitary conditions and medical treatment here protect children better than extra weight.

- In many of the countries that immigrants come from, weight is seen as a sign of wealth and prosperity. It has the same cultural value as extreme thinness has in our culture – treat it as a cultural as well as a medical issue for better success.

Infant Health

- It is very important to avoid making too many positive comments about a baby's general health.
  - Among traditional Hmong, saying a baby is "pretty" or "cute" may be seen as a threat because of fears that spirits will be attracted to the child and take it away
  - Some traditional Latinos will avoid praise to avoid attracting the "evil eye"
  - Some Vietnamese consider profuse praise as mockery

- It is often better to focus on the quality of the mother's care – "the baby looks like you take care of him well."

- Talking about a new baby is an excellent time to introduce the idea that preventive medicine should be a regular part of the new child's experience. Well-baby visits may be an entirely new concept to some new mothers from other countries. Protective immunizations are often the most accepted form of preventive medicine. It may be helpful to explain well-baby visits and check-ups as a kind of extension of the immunization process.

Substance Abuse

- When asking question regarding issues of substance (or physical) abuse, concerns about family honor and privacy may come into play. For example, in Vietnamese and Chinese cultures family loyalty, hierarchy, and filial piety are of the utmost importance and may therefore have a direct effect on how a patient responds to questioning, especially if family members are in the same room. Separating family members, even if there is some resistance to the idea, may be the only way to accurately assess some of these problems.

- Gender roles are often expressed in the use or avoidance of many substances, especially alcohol and cigarettes. When discussing and treating these issues the social component of the abuse needs to be considered in the context of the patient's culture.

- Alcohol is considered part of the meal in many societies, and should be discussed together with eating and other dietary issues.

Physical Abuse

- Ideas about acceptable forms of discipline vary from culture to culture. In particular, various forms of corporal punishment are accepted in many places. Emphasis must be placed on what is acceptable ***here***, and what may cause physical harm.

- Women may have been raised with different standards of personal control and autonomy than we expect in the United States. They may be accepting physical abuse *not* because of feelings of low self-esteem, but because it is socially accepted among their peers, or because they have nobody they can go to with their concerns. It is important to treat these cases as social rather than psychological problems.

- Immigrants learn quickly that abuse is reported and will lead to intervention by police and social workers. Even victims may not trust doctors, social workers, or police. It may take time and repeated visits to win the trust of patients. Remind patients that they do not have to answer questions (silence may tell you more than misleading answers). Using depersonalized conversational methods will increase success in reaching reluctant patients.

- Families may have members with conflicting values and rules for acceptable behavior that may result in conflicting reports about suspected physical abuse. This does not necessarily mean that anyone is being deceptive, just seeing things differently. This may cause special difficulties for teens who may have adopted new cultural values common to Western society, but must live in families that have different standards and behaviors.

- Behavioral indicators of abuse are different in different cultures. Many people are not very emotionally and physically expressive of physical and mental pain. Learn about the cultural norms of your patient populations to avoid overlooking or misinterpreting unknown signs of trauma.

- Do not confuse physical evidence of traditional treatments with physical abuse. Acceptable traditional treatments, such as coin rubbing or cupping, may leave marks on the skin, which look like physical abuse. Always consider this possibility if you know the family uses traditional home remedies.

CULTURAL BACKGROUND – (continued)

Communicating with the Elderly

- Always address older patients using formal terms of address unless you are directly told that you may use personal names. Also remind staff that they should do the same.

- Stay aware of how the physical setting may be affecting the patient. Background noise, glaring or reflecting light, and small print forms are examples of things that may interfere with communication. The patients may not say anything, or even be aware that something physical is interfering with their understanding.

- Stay aware that many people believe that giving a patient a terminal prognosis is unlucky or will bring death sooner and families may not want the patient to know exactly what is expected to happen. If the family has strong beliefs along these lines the patient probably shares them. Follow ethical and legal requirements, but stay cognizant of the patient's cultural perspective. Offer the opportunity to learn the truth, at whatever level of detail desired by the patient.

- It is important to explain the specific needs for having an advance directive before talking about the treatment choices and instructions. This will help alleviate concerns that an advance directive is for the benefit of the medical staff rather than the patient.

- Elderly, low-literacy patients may be very skilled at disguising their lack of reading skills and may feel stigmatized by their inability to read. If you suspect this is the case you should not draw attention to this issue but seek out other methods of communication.

PARTNERING WITH DIVERSE PATIENTS: TIPS FOR OFFICE STAFF TO ENHANCE COMMUNICATION

1. **Build rapport with the patient.**
   - Address patients by their last name. If the patient's preference is not clear, ask, "How would you like to be addressed?"
   - Focus your attention on patients when addressing them.
   - Learn basic words in your patient's primary language, like "hello" or "thank you".
   - Recognize that patients from diverse backgrounds may have different communication needs.
   - Explain the different roles of people who work in the office.

2. **Make sure patients know what you do.**
   - Take a few moments to prepare a handout that explains office hours, how to contact the office when it is closed, and how the PCP arranges for care (i.e. PCP is the first point of contact and refers to specialists).
   - Have instructions available in the common language(s) spoken by your patient base.

3. **Keep patients' expectations realistic.**
   - Inform patients of delays or extended waiting times. If the wait is longer than 15 minutes, encourage the patient to make a list of questions for the doctor, review health materials or view waiting room videos.

4. **Work to build patients' trust in you.**
   - Inform patients of office procedures such as when they can expect a call with lab results, how follow-up appointments are scheduled, and routine wait times.

5. **Determine if the patient needs an interpreter for the visit.**
   - Document the patient's preferred language in the patient chart.
   - Have an interpreter access plan. An interpreter with a medical background is preferred to family or friends of the patient.
   - Assess your bilingual staff for interpreter abilities. (see Employee Language Skills Self-Assessment Tool).
   - Possible resources for interpreter services are available from health plans, the state health department, and the Internet. See contracted health plans for applicable payment processes.

6. **Give patients the information they need.**
   - Have topic-specific health education materials in languages that reflect your patient base. (Contact your contracting health plans/contracted medical groups for resources.)
   - Offer handouts such as immunization guidelines for adults and children, screening guidelines, and culturally relevant dietary guidelines for diabetes or weight loss.

7. **Make sure patients know what to do.**
   - Review any follow-up procedures with the patient before he or she leaves your office.
   - Verify call back numbers, the locations for follow-up services such as labs, X-ray or screening tests, and whether or not a follow-up appointment is necessary.
   - Develop pre-printed simple handouts of frequently used instructions, and translate the handouts into the common language(s) spoken by your patient base. (Contact your contracting health plans/contracted medical groups for resources.)

WORKING WITH DIVERSE PATIENTS: TIPS FOR SUCCESSFUL PATIENT ENCOUNTERS

To enhance patient/provider communication and to avoid being unintentionally insulting or patronizing, be aware of the following:

Styles of Speech: *People vary greatly in length of time between comment and response, the speed of their speech, and their willingness to interrupt.*

- Tolerate gaps between questions and answers, impatience can be seen as a sign of disrespect.
- Listen to the volume and speed of the patient's speech as well as the content. Modify your own speech to more closely match that of the patient to make them more comfortable.
- Rapid exchanges, and even interruptions, are a part of some conversational styles. Don't be offended if no offense is intended when a patient interrupts you.
- Stay aware of your own pattern of interruptions, especially if the patient is older than you are.

Eye Contact: *The way people interpret various types of eye contact is tied to cultural background and life experience.*

- Most Euro-Americans expect to look people directly in the eyes and interpret failure to do so as a sign of dishonesty or disrespect.
- For many other cultures direct gazing is considered rude or disrespectful. Never force a patient to make eye contact with you.
- If a patient seems uncomfortable with direct gazes, try sitting next to them instead of across from them.

Body Language: *Sociologists say that 80% of communication is non-verbal. The meaning of body language varies greatly by culture, class, gender, and age.*

- Follow the patient's lead on physical distance and touching. If the patient moves closer to you or touches you, you may do the same. However, stay sensitive to those who do not feel comfortable, and ask permission to touch them.
- Gestures can mean very different things to different people. Be very conservative in your own use of gestures and body language. Ask patients about unknown gestures or reactions.
- Do not interpret a patient's feelings or level of pain just from facial expressions. The way that pain or fear is expressed is closely tied to a person's cultural and personal background.

Gently Guide Patient Conversation: *English predisposes us to a direct communication style, however other languages and cultures differ.*

- Initial greetings can set the tone for the visit. Many older people from traditional societies expect to be addressed more formally, no matter how long they have known their physician. If the patient's preference is not clear, ask how they would like to be addressed.
- Patients from other language or cultural backgrounds may be less likely to ask questions and more likely to answer questions through narrative than with direct responses. Facilitate patient-centered communication by asking open-ended questions whenever possible.
- Avoid questions that can be answered with "yes" or "no." Research indicates that when patients, regardless of cultural background, are asked, "Do you understand," many will answer, "yes" even when they really do not understand. This tends to be more common in teens and older patients.
- Steer the patient back to the topic by asking a question that clearly demonstrates that you are listening. Some patients can tell you more about their health through story telling than by answering direct questions.

TIPS FOR LOCATING INTERPRETER SERVICES

First, assess the oral linguistic needs of your Limited English Proficient (LEP) patients. Second, assess the services available to meet these needs.

<u>Assess the language capability</u> of your staff *(See Employee Language Skills Self-Assessment)*

- Keep a list of available bilingual staff who can assist with LEP patients on-site.

<u>Assess services available</u> through patient health plans

- Ask all health plans you work with if and when they provide interpreter services, including American Sign Language interpreters, as a covered benefit for their members.
- Identify the policies and procedures in place to access interpreter services for each plan you work with.
- Keep an updated list of specific telephone numbers and health plan contacts for language services.
- Ask the agency providing the interpreter for their training standards and methods of assessing interpreter quality.
- Don't forget to inquire about Telecommunication Device for the Deaf (TDD) services for the hard of hearing/deaf.

If services are covered, <u>identify the appropriate contact</u> and request the health plan's process to access services.

- Determine if face-to-face and/or telephone interpreters are covered.
- If face-to-face interpreters are covered, have the following information ready before requesting the interpreter: gender, age, language needed, date/time of appointment, type of visit, and office specialty.
    - ➢ *Remember to follow all HIPAA regulations when transmitting any patient-identifiable information to parties outside your office.*
- If telephone interpreters are covered, relay the pertinent patient information which will help the interpreter better serve the needs of the patient and the provider.

If interpreter services are NOT covered by the patient's health plan, **<u>find other resources</u>** to meet the linguistic needs of your LEP patients.

- Use trained/capable internal staff.
- Contract with a telephonic interpreting company. (See *Telephonic Interpreting Companies.*) It is recommended that you assess the quality of the services provided by these vendors.
- Check for services available through Community Based Organizations. Some provide free face-to-face interpreter services for the community or they may offer low fees.
- Depending on the linguistic needs of your LEP population, you may have to consider hiring a professional interpreter.
- For further information, you may contact the National Council on Interpretation in Health Care, the Society of American Interpreters, the Translators & Interpreters Guild, the American Translators Association, or any local Health Care Interpreters association in your area.

10 TIPS FOR WORKING WITH INTERPRETERS

1. **Choose an interpreter who meets the needs of the patient, considering age, sex and background.**

   A patient might be reluctant to disclose personal and sensitive information, for example, in front of an interpreter of a different sex.

2. **Hold a brief introductory discussion with the interpreter.**

   If it is your first time working with a professional interpreter, briefly meet with the interpreter first to agree on basic interpretation protocols. Let the interpreter brief the patient on the interpreter's role.

3. **Allow enough time for the interpreted sessions.**

   Remember that an interpreted conversation requires more time. What can be said in a few words in one language may require a lengthy paraphrase in another.

4. **Speak in a normal voice, clearly, and not too fast or too loudly.**

   It is usually easier for the interpreter to understand speech produced at normal speed and with normal rhythms, than artificially slow speech.

5. **Avoid acronyms, jargon, and technical terms**.

   Avoid idioms, technical words, or cultural references that might be difficult to translate. Some concepts may be easy for the interpreter to understand but extremely difficult to translate (i.e. positive test results).

6. **Face the patient and talk to the patient directly. Be brief, explicit and basic.**

   Remember that you are communicating with the patient through an interpreter. Pause after a full thought for the interpretation to be accurate and complete. If you speak too long, the interpreter may not remember and miss what was said.

7. **Don't ask or say anything that you don't want the patient to hear.**

   Expect everything you say to be interpreted, and everything the patient and their family says.

8. **Be patient and avoid interrupting during interpretation.**

   Allow the interpreter as much time as necessary to ask questions, for repeats, and for clarification. Be prepared to repeat yourself in different words if your message is not understood. Professional interpreters do not translate word-for-word but rather concept-by-concept. Also remember that English is a direct language, and may need to be relayed into complex grammar and a different communication pattern.

9. **Be sensitive to appropriate communication standards.**

   Different cultures have different protocols to discuss sensitive topics and to address physicians. Many ideas taken for granted in America do not exist in the patient's culture and may need detailed explanation in another language. Take advantage of your interpreter's insight and let the interpreter be your "Cultural Broker."

10. **Read body language in the cultural context.**

    Watch the patient's eyes, facial expression, or body language when you speak and when the interpreter speaks. Look for signs of comprehension, confusion, agreement, or disagreement.

Note: *When working with interpreters, reassure the patient that the information will be kept confidential.*

TALKING ABOUT END OF LIFE CARE AND ADVANCE DIRECTIVES ACROSS CULTURES

Your ability to discuss advance directives and end-of-life care with patients from diverse backgrounds can be improved with a better understanding of the differences in beliefs, practices and attitudes toward death and dying. The following provides some important information about the cultural variations you may encounter during your discussions.

Knowledge about particular cultural groups should serve only as a guideline to begin asking questions regarding individual beliefs and behaviors. Patients and their families may or may not subscribe to cultural norms.

AREAS OF CULTURAL VARIATION	POINTS TO CONSIDER	SUGGESTIONS
Talking about end of life care	• Not all cultures prefer direct disclosure of a serious illness. Disclosure may be viewed as disrespectful, impolite, harmful and/or burdensome. In many cultures, the elderly are considered more vulnerable to 'bad news' and it may provoke depression or eliminate hope. • Historical and contemporary racism may lead some patients to see the healthcare system as untrustworthy. Those communities with a history of suffering from discrimination may fear neglect if they do not insist on maximal care. • For some cultures, discussing cancer is taboo and shameful, as it is believed to be caused by a wrongdoing in a past life. It may have a negative impact on the family's social status in the community.	**General Guidelines:** • Establish trust by eliciting information through active, non-judgmental listening to the patient and family. Demonstrate curiosity. Assess each individual in the context of his/her family and culture. Be respectful of the patient's understanding of the cause of the illness and preferences for end of life care. • Seek information about cultural norms of your patient base. Consider sociopolitical and historical facts that may influence beliefs about illness, healthcare and death such as poverty, discrimination, refugee status, and healthcare access issues. • Work from a place of shared values, Find a common ground and introduce information gradually. Beware of jargon. Assess the language the patient and family use in discussing the illness, including the extent of openness with regard to diagnosis, prognosis and death. Let the patient and family guide you regarding preference for disclosure. • If the word "cancer" is considered taboo, consider alternative descriptors such as 'growth' or 'mass'. • Use trained healthcare interpreters when language barriers are identified.

	• Some patients believe that negative words spoken aloud and direct questions of mortality or thoughts about illness and death may become self-fulfilling.	**Possible Cross Cultural Interview Questions:** • "Is there anything that would be helpful for me to know about how your family, community, and/or religious faith views this illness and treatment?" • "What questions do you have? How much do you want to know?" • "Sometimes people are uncomfortable discussing these issues with a doctor who is of a different race or cultural background. Are you comfortable with me treating you? Will you please let me know if there is anything about your background that would be helpful for me to know in working with you or your family?"
Spiritual and religious beliefs about end of life	• While many people have a spiritual or transcendent dimension to his or her life, not all believe in an afterlife. • For some, death may be an extremely fearful process. • Religious perspectives, beliefs and practices may override one's cultural background. • For some, death is merely a path to get to where we are going. For others it is a struggle to be overcome. • Some patients feel that death is an "act of God" or a "Supreme Being". It is inappropriate to question God's decisions. • Many patients seek aggressive treatment because they value the sanctity of life, not because they misunderstand the limits of technology. Some	• Seek information about the spiritual beliefs and practices common to your patient base. Solicit information from all possible sources within the community, including religious leaders. • Assess religious beliefs of the patient and family. Focus on the meaning of death, the existence of an afterlife, and belief in miracles. Establish beliefs about the body after death (i.e., who owns the body and how is it to be treated.) • Ask your patient: "What role does religion play in your decisions related to this illness and treatment." • Consultation with the family and Spiritual Counselor will help you assess what is appropriate and acceptable. Variation from standard treatment regimens may be necessary to accommodate religious practices.

	strongly believe that each life is unique and must not be destroyed. • For some, survival alone is an important demonstration of faith. • In some religions, withholding food is strictly forbidden.	

TALKING ABOUT END OF LIFE CARE AND ADVANCE DIRECTIVES ACROSS CULTURES (continued)

AREAS OF CULTURAL VARIATION	POINTS TO CONSIDER	SUGGESTIONS
Decision making locus of control	• Decision models to handle terminal medical decisions and end-of-life care include autonomous, family based, physician based and shared physician-family decision-making. • Patients may exercise autonomy by choosing "not to know". • Cultural issues around truth telling occur in many cultures and there are variations among members of the same culture and even in the patient's family. • Working with families can be challenging especially when family members do not share the same cultural assumptions about end of life care. • The definition of family may include extended, immediate and non-blood kinship. • Distrust or unfamiliarity of the US health care system, health care disparities, cultural perspective on death and suffering, and family dynamics all contribute to the type of model used by different ethnic groups. • Those who practice a family based decision making model have relatives or extended family make choices, at times	**General Guidelines:** • Determine the locus of control over decision-making. Is it the individual patient, the family, or another social unit? • Solicit the patient and family views about the location and timing of death including the preferred role of family members and health care providers. • Consider gender issues and power relationships within the decision-making unit. • Offer the patient the opportunity to learn the truth at the level of detail desired. Allow some decisions about who is responsible for knowing about his/her care. **Possible Cross Cultural Interview Questions:** • "Some people want to know everything about their medical condition, and others do not. What is your preference?" • Do you prefer to make medical decisions about future tests or treatment yourself, or would you prefer that someone else make them for you?" • "Your condition requires several decisions to be made about your treatment. Is there someone, perhaps a family member, who you would like to be with you when we discuss these matters?" • "Some people really do not want to be told what is wrong with them, but would rather their families be told instead. What do you prefer?" • "Would you be more comfortable if I spoke to your (daughter, son, brother...) alone, or

	without the patient’s input. • Some cultures practice filial piety, including the responsibility to care and protect the elderly from terminal diagnosis and prognosis. • For some ethnic communities, decisions that are too individualistic – not taking into consideration the affect on the family or consulting the family, is seen as disrespectful to the family and ethnic community. • For some, physicians may share decisions, as they are seen as the ‘expert’.	would you like to be present?” *If the patient chooses not to be present:* “If you change your mind at any point and would like more information, please let me know. I will answer any questions you have.” (*Document the exchange in medical record.*)
Advance directives	• There are significantly lower completion rates of Advance Directives among minority groups. Causes may be due to distrust of the healthcare system, historical misuse of signed documents, healthcare disparities, or cultural perspectives on death and suffering. • Direct discussion of advance directives may be undesirable in situations in which they are viewed as potentially harmful to the patient’s well being. • Some do not want to burden children by assigning someone to be the head decision maker. The preference is for the family to make a group decision.	• Inform patients and family members about the availability of written advance directives and durable power of attorney. Provide them in the appropriate language. • Encourage open dialogue about any quality of care concerns.

Special Needs	• Some patients will have cognitive dysfunction. • Many patients have sensory (visual or hearing) deficits. • It is not uncommon for depression to occur.	• In the case of cognitive dysfunction, include the patient to the greatest extent possible. Rely on family and advance directives for guidance and on the patient's nonverbal communication for assessing patient comfort. • To maximize the sensory impaired patient's ability to participate, create a quiet, well-lit, comfortable space that enhances communication. Inexpensive headset hearing amplifiers can improve the interaction. • Treating depression will allow the patient to take a more active role. The existence of depression, however, should not limit discussions.

* **NOTE: Avoid** using family members as interpreters. **Minors** are **prohibited** from being used as interpreters. Find an interpreter with a health care background. When physician-patient communication occurs through an interpreter, trained health care interpreters make fewer errors than untrained interpreters. **Document** in the patient's medical chart the request for or refusal of an interpreter.

PAIN MANAGEMENT ACROSS CULTURES

Your ability to provide adequate pain management to some patients can be improved with a better understanding of the differences in the way people deal with pain. Here is some important information about the cultural variations you may encounter when you treat patients for pain management.

These tips are generalizations only. It is important to remember that each patient should be treated as an individual.

AREAS OF CULTURAL VARIATION	POINTS TO CONSIDER	SUGGESTIONS
Reaction to pain and expression of pain	• Cultures vary in what is considered acceptable expression of pain. As a result, expression of pain will vary from stoic to extremely expressive for the same level of pain. • Some men may not verbalize or express pain because they believe their masculinity will be questioned.	• Do not mistake lack of verbal or facial expression for lack of pain. Under-treatment of pain is a problem in populations where stoicism is a cultural norm. • Because the expression of pain varies, ***ask*** the patient what level, or how much, pain relief they think they need. • Do not be judgmental about the way someone is expressing their pain, even if it seems excessive or inappropriate to you. The way a person in pain behaves is socially learned.
Spiritual and religious beliefs about using pain medication	• Members of several faiths will not take pain relief medications on religious fast days, such as Yom Kippur or daylight hours of Ramadan. For these patients, religious observance may be more important than pain relief. • Other religious traditions forbid the use of narcotics. • Spiritual or religious traditions may affect a patient's preference for the form of medication delivery, oral, IV, or IM.	• Consultation with the family and Spiritual Counselor will help you assess what is appropriate and acceptable. Variation from standard treatment regimens may be necessary to accommodate religious practices. • Accommodating religious preferences, when possible, will improve the effectiveness of the pain relief treatment. • Offer a choice of medication delivery. If the choice is less than optimal, ask why the patient has that preference and negotiate treatment for best results.

PAIN MANAGEMENT ACROSS CULTURES (continued)

AREAS OF CULTURAL VARIATION	POINTS TO CONSIDER	SUGGESTIONS
Beliefs about drug addiction	• Recent research has shown that people from different genetic backgrounds react to pain medication differently. Family history and community tradition may contain evidence about specific medication effects in the population. • Past negative experience with pain medication shapes current community beliefs, even if the medications and doses have changed.	• Be aware of potential differences in the way medication acts in different populations. A patient's belief that they are more easily addicted may have a basis in fact. • Explain how the determination of type and amount of medication is made. Explain changes from past practices. • Assure your patient you are watching their particular case.
Use of alternative pain relief treatment	• Your patient may be using traditional pain relief treatment, such as herbal compresses or teas, massage, acupuncture or breathing exercises.	• Respectfully inquire about all of the ways the patient is treating their pain. • Use indirect questions about community or family traditions for pain management to provide hints about what the patient may be using. There may be some reluctance to tell you about alternative therapies until they feel it is "safe" to talk about them. • Accommodate or integrate your treatments with alternative treatments when possible.
Methods needed to assess pain	• Most patients are able to describe their pain using a progressive scale, but others are not comfortable using a numerical scale, and the scale of facial expressions (smile to grimace) may be more useful.	• Ask the patient specifically how they can best describe their pain. • Use multiple methods of assessing pain - scales and analogies, if you feel the assessment of pain is producing ambiguous or incorrect results. • Once the severity of the pain can be assessed, explain in detail the expected result of the use of the pain medication in terms of whatever descriptive tools the patient has used. Check comprehension with teach-back techniques. • Instead of using scales, which might not be known to the patient, asking for comparative analogies, such as "like a burn from a stove," "cutting with a knife," or "stepping on a stone," may produce a more accurate description.

* **NOTE: Avoid** using family members as interpreters. **Minors** are **prohibited** from being used as interpreters. Find an interpreter with a health care background. **Document** in the patient's medical chart the request for or refusal of an interpreter.

Case Management Palliative Care Pilot Program

Offered by Blue Cross & Blue Shield of Rhode Island

Blue Cross & Blue Shield of Rhode Island (BCBSRI) is pleased to announce a Palliative Care Pilot Program for your patients who are BlueCHiP for Medicare members. This is an alternative benefit offered by BCBSRI.* Palliative care is often a bridge between skilled home care and hospice care. This care typically involves many of the services included in a hospice program, but does not require a life expectancy of six months or less. Your patients who are suffering from deteriorating condition(s) can benefit from this program.

Our Palliative Care Pilot Program takes a multidisciplinary team approach and uses home-based intervention by a home care agency **in collaboration with the physician**. This patient-centered program:

- Educates patients on advance care planning.
- Enhances continuity of care.
- Helps to alleviate complex issues during advanced illness.

The goals of this program are to **prevent and relieve suffering;** to support **best possible quality of life** for members and their families; to **optimize functions** and provide information to help in decision making; and to educate regarding **advanced care directives**.

Who is eligible?

Your BlueCHiP for Medicare patients who meet the conditions below may be candidates for this program:

- Patient who has a life-limiting illness ("Condition for which the need for symptom management exceeds the response to aggressive treatment.")
- Patient who does not qualify for hospice at this time (life expectancy > 6 months but estimated at no more than 12 months) or may not be ready or willing to accept hospice.
- Screening eligibility may include cancer, end-stage chronic obstructive pulmonary disease, end-stage renal disease, dementia, neurological, and other life-limiting illness.**

What services are available?

Patients who elect to participate in this program have access to a professional staff 24 hours per day, seven days per week. This professional staff offers skills in understanding advanced illness and the grieving process, and includes RNs, certified nursing assistants, social workers, a physical therapist, an occupational therapist, a speech therapist, and a nutritionist.

What are the desired outcomes?

Our goals are to:

- Improve symptom and pain management.
- Assist member in completion of advanced care directives.
- Prepare and support both member and family with the changes advanced illnesses can bring.

To refer any of your patients who are eligible for this pilot program, please contact Case Managers Rita Maynard, RN, at **(401) 459-5129** or Alice Hoskins, RN, at **(401) 459-5006**. Fax **(401) 459-5804.**

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* *Alternative benefits are extended benefits, which are time-limited authorizations for services that are not normally covered. These extended benefits are offered at the corporation's discretion per our alternative benefit policy.*

** *BCBSRI case managers have the authority to determine, based on Palliative Care Screening Tool Score, whether a member is accepted into the pilot program.*

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Advance Care Planning Situational Quiz

M1-1. Mrs. Lanzini is a 68-year-old widow with 4 living adult children who has advanced congestive heart failure, New York Heart Association class IV, despite optimal afterload reduction and diuretic therapy. During an office visit, after a full discussion, she indicates that she would like her priest to make medical decisions for her in accordance with Catholic doctrine in the event she cannot make decisions for herself. The best advice you should give her is to:

a. write a letter to the doctor indicating her wishes
b. complete a statutory living will
c. complete a Statutory Power of Attorney for Health Affairs
d. choose one of her children to make decision for her

Answer: c

The question is aimed at determining knowledge. The only legally recognized way that the patient can authorize someone to make medical decisions for her, other than her legal next of kin, is through the Statutory Power of Attorney for Health Affairs. A letter to the doctor would support this choice, and help the physician determine if the power of attorney were acting in her best interests. In most states, a Living Will is only operative if it is determined that she has a terminal illness and is unable to make decisions. She has the ability to choose anyone she wants as an agent; there is no need to choose her child.

M1-2. Mr. Robinson is a 34-year-old pipe fitter who has been admitted with liver failure secondary to hepatitis. He lacks capacity to make decisions for himself. He has not indicated any prior wishes or completed any advance directive form. The physician is best guided by:

a. duty to prolong life at all cost
b. medical judgment about what is best
c. state law governing substituted judgment
d. the family’s wishes even though the physician suspects selfish motives

Answer: c

This question is aimed at the issue of substituted judgment in the absence of written advance directives. Laws governing who makes decisions for the patient in the absence of clear evidence about what the patient wanted vary from state to state. Many, but not all, recognize “next of kin” in the absence of written directives. Although medical judgment is important, it is advisory to the person who has the authority to speak for the patient. This is determined by state law. The family is not always the best decision maker.

M1-3. Miss Monadnock is a 93-year-old former waitress with osteoarthritis, hypertension, and a prolapsed mitral valve. She completed a Living Will and named her niece as her power of attorney for health affairs some time ago. She was hospitalized for pneumonia, 3 months ago. In accordance with her wishes, she was intubated for 5 days and had an extended period of recovery. She is again living alone in her own home. On what occasion(s) should her plans be revisited?

a. at the next suitable office visit
b. when the patient develops moderate atrial fibrillation
c. neither
d. both

Answer: d
This question is aimed at understanding how advance care planning should be woven throughout a care plan. Appropriate times to review advance directives are both when things are going well (particularly after a major health care event) and with new developments. They shouldn't be accomplished once and never reviewed again.

M1-4. Mr Arteresian is an 84-year-old retired judge recently discharged from the hospital for evaluation of syncope. He completed a Living Will and named his son as his power of attorney for property and health affairs. In the office, he says he would also like to make plans about his funeral and wants to arrange for his body to go to the medical school. Your best response is to:

a. tell him to talk to his son
b. note this is the medical record
c. both of the above
d. neither of the above

Answer: c
This question is aimed at the larger sphere of advance planning that is appropriate for patients with advanced disease. His son, as power of attorney for property, will be responsible for his father's affairs after death, including disposition of his body. The information that the son is power of attorney for health affairs and property as well as the father's wishes is useful in the medical record both to ensure that the power of attorney acts in accordance with the patient's best interests and to ensure continuity and communication.

Pain Management Situational Quiz

M4-1. Neuropathic pain is:

- a. usually treated with anti-inflammatory agents
- b. a result of disordered nerve function
- c. due to direct stimulation of intact nociceptors
- d. rarely responsive to opioid analgesics

Answer: b

This question concerns understanding pain pathophysiology. Neuropathic pain is a result of disordered nerve function. It does not result from inflammatory processes and does not relate to ongoing stimulation of intact nociceptors. Opioids are effective in managing neuropathic pain. However, relief is usually incomplete without the addition of adjuvant or coanalgesics.

M4-2. Mrs Martinez is a 42-year-old woman who has breast cancer metastic to bone and liver. Her pain has been well controlled on sustained-release morphine, 120 mg po bid, for 3 months. Which of the following is most likely to occur as a result of this treatment?

- a. psychological dependence
- b. physical dependence
- c. pharmacologic tolerance
- d. respiratory depression

Answer: b

This question is aimed at understanding pharmacology of opioids. Physical dependence (the appearance of a withdrawal syndrome if the drug is stopped suddenly) should be expected. Now that she is on a stable dose, the dose is unlikely to need to be escalated unless her disease worsens. Progressive pharmacologic tolerance is unlikely. There is no evidence that opioids cause psychological dependence. Respiratory depression in an otherwise well woman should be expected.

M4-3. Mr Martin has locally advanced transitional cell cancer of the bladder with chronic pelvic and abdominal pain. Which of the following is most important in determining the maximum dose of oral morphine during dose titration?

a. pain relief
b. respiratory depression
c. risk of overstepping regulatory limits
d. strength of pill

Answer: a

This question is aimed at understanding pharmacology of opioids. There is no upper limit to pure agonist opioid analgesics. The dose is limited by side effects. Respiratory depression is exceedingly uncommon when doses are titrated to pain relief. There are no a priori limits to morphine dose escalation. Pill strength is not an issue —patients may need to take many pills to achieve the desired dose.

M4-4. Pharmacologic tolerance develops to all of the following side effects of opioid analgesics *except*:

- a. constipation
- b. nausea
- c. respiratory depression
- d. sedation

Answer: a

This question is aimed at understanding adverse effects of opioids. Constipation is nearly universal and does not get better with repeated dosing. Pharmacological tolerance develops within days to weeks to the common adverse effects such as nausea and sedation, as well as to the uncommon effect of respiratory depression.

REPORT BRIEF • APRIL 2004

HEALTH LITERACY: A PRESCRIPTION TO END CONFUSION

Nearly half of all American adults—90 million people—have difficulty understanding and acting upon health information. The following two examples were selected from the many pieces of complex consumer health information used in America:

- From an informed consent form: *A comparison of the effectiveness of educational media in combination with a counseling method on smoking habits is being examined; and*
- From a consumer privacy notice: *Examples of such mandatory disclosures include notifying state or local health authorities regarding particular communicable diseases.*

Forty million Americans cannot read complex texts like these at all, and 90 million have difficulty understanding complex texts. Yet complex text is very common in health information, from insurance forms to advertising. Even people with strong literacy skills may have trouble obtaining, understanding, and using complex health information: a surgeon may have trouble helping a family member with Medicare forms; a science teacher may not understand information sent by a doctor about a brain function test; and an accountant may not know when to get a mammogram. Health literacy could help end this confusion.

...90 million people have difficulty understanding and acting upon health information.

WHAT IS HEALTH LITERACY?

Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. But health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of health information and care providers: our doctors; nurses; administrators; home health workers; the media; and many others.

...health literacy may affect the health of Americans and the ability of the health care system to provide effective, high-quality health care.

WHY IS HEALTH LITERACY IMPORTANT?

Although causal relationships between limited health literacy and health outcomes are not yet established, cumulative and consistent findings suggest such a causal connection. This means that health literacy may affect the health of Americans and the ability of the health care system to provide effective, high-quality health care. Studies have shown that people with low health literacy understand health information less well, get less preventive health care—such as screenings for cancer—and use expensive health services such as emergency department care more frequently.

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IS HEALTH LITERACY ABOUT EDUCATION?

Health literacy is not only about education. A person who has finished high school and knows how to read may still not be able to navigate the health system. Health literacy comes from a convergence of education, cultural and social factors, and health services. While reading, writing, and math skills make up part of the basis of health literacy, many other skills and abilities are also important, such as speaking, listening, having adequate background information, and being able to advocate for oneself in the health system.

A person who has finished high school and knows how to read may still not be able to navigate the health system.

WHAT CAN BE DONE ABOUT LOW HEALTH LITERACY?

Research shows that health literacy can be improved. Efforts to improve health literacy in the United States must depend on efforts from all the sectors that contribute to the problem: government; schools; and the health care system. To start reducing the negative effects of limited health literacy, health service providers and people in the community must be knowledgeable, aware, and responsive to the health literacy of patients and consumers. In order to promote a health literate America:

- The Department of Health and Human Services should take the lead in developing uniform standards for addressing health literacy;
- Government and private funders should support the development and use of culturally appropriate new measures of health literacy, as well as mulitdisciplinary research on the extent, associations, and consequences of limited health literacy;
- Educators should take advantage of opportunities to incorporate health-related tasks, materials, and examples into existing lesson plans;
- Professional schools and continuing education programs in the health fields should incorporate health literacy into their curricula and areas of competence; and
- Health care systems should develop and support demonstration programs to establish effective approaches to reduce the negative effects of limited health literacy.

* * * * * * * * *

COMMITTEE ON HEALTH LITERACY. David Kindig MD, PhD (Chair); Dyanne Affonso RN, PhD; Eric Chudler PhD; Marilyn Gaston, MD; Cathy Meade RN, PhD; Ruth Parker MD; Victoria Purcell-Gates PhD; Rima Rudd ScD; Irving Rootman PhD; Susan Scrimshaw PhD; William Smith PhD.

Health Literacy: A Prescription to End Confusion is available for sale from the National Academies Press, 500 Fifth St. NW, Washington, DC 20001; call (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area), or visit the NAP's on-line bookstore at **www.nap.edu**. For more information about the Institute of Medicine, visit the IOM home page at **www.iom.edu**.

Agency for Healthcare Research and Quality

Evidence Report/Technology Assessment

Number 87

Literacy and Health Outcomes

Summary

Introduction

Literacy can be defined as "an individual's ability to read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and to develop one's knowledge and potential."[1] Literacy sometimes describes a person's facility with or knowledge about a particular topic (e.g., "computer literacy"). In that context, "health literacy" is a constellation of skills that constitute the ability to perform basic reading and numerical tasks for functioning in the health care environment and acting on health care information.[2] Some authors include in this definition a working knowledge of disease processes, self-efficacy, and motivation for political action regarding health issues.[3]

Instruments for measuring literacy in the health care setting have focused on the ability to read and, in some cases, to use numbers. Commonly used are the Wide Range Achievement Test (WRAT) reading subtest,[4] the Rapid Estimate of Adult Literacy in Medicine (REALM),[5] and the Test of Functional Health Literacy in Adults (TOFHLA).[6] The WRAT and REALM are word recognition tests validated as instruments of reading ability;they are highly correlated with one another and with other traditional reading assessments.[5] The TOFHLA assesses literacy by a modified Cloze method: subjects read passages in which every fifth to seventh word has been deleted and insert the correct word from a choice of four words.[6] The TOFHLA also has subjects respond to prompts, such as pill bottle instructions and appointment slips, thus measuring patients' ability to use basic numerical information (numeracy). A short version (S-TOFHLA) involves only two reading comprehension sections. All of these instruments are highly correlated with one another.

Low literacy is common in the United States; a decade ago, 40 million adult Americans scored on the lowest of five levels (level 1) of the National Adult Literacy Survey (NALS); another 50 million scored at level 2.[7] These levels correspond to having trouble finding pieces of information or numbers in a lengthy text, integrating multiple pieces of information in a document, or finding two or more numbers in a chart and performing a calculation.[7] Meeting the requirements of an ever-increasing percentage of jobs and the many demands of day-to-day life requires skill above these NALS levels.[8]

Low literacy may impair functioning in the health care environment, affect patient-physician communication dynamics, and inadvertently lead to substandard medical care.[2,9] It is associated with poor understanding of written or spoken medical advice, adverse health outcomes, and negative effects on the health of the population.[6,10]

Certain groups have an especially high prevalence of low literacy. They include people who completed fewer years of education, persons of certain racial or ethnic groups, the elderly,[7] and persons with lower cognitive ability.[11] Other factors associated with lower literacy include living in the South or Northeast (rather than the West and Midwest), female sex, incarceration, and income status classified as poor or near poor.

Given that low literacy may affect health and well-being negatively, the Agency for Healthcare Research and Quality (AHRQ) commissioned an evidence report from the RTI

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International–University of North Carolina Evidence-based Practice Center (RTI-UNC EPC). Literacy and health are of particular concern to the American Medical Association (AMA), which originally nominated the topic. Our systematic review consolidates and analyzes the body of literature that has been produced to date regarding the relationship between literacy and health outcomes and the evidence about interventions intended to improve the health of people with low literacy.

Methods

We examined two key questions in this review.

- Key question 1: Are literacy skills related to
  - a. use of health care services?
  - b. health outcomes?
  - c. costs of health care?
  - d. disparities in health outcomes or health care service use according to race, ethnicity, culture, or age?
- Key question 2: For individuals with low literacy skills, what are effective interventions to
  - a. improve use of health care services?
  - b. improve health outcomes?
  - c. affect the costs of health care?
  - d. improve health outcomes and/or health care service use among different racial, ethnic, cultural, or age groups?

Our inclusion/exclusion criteria limited studies to those with outcomes related to health and health services, studies published from 1980 on, and studies conducted in developed countries (United States, Canada, the United Kingdom, Australia, New Zealand, and Europe). Study participants included individuals of all ages.

We searched several databases, using terms such as "literacy" and "health literacy" and, in some cases, "numeracy" and the name or accepted acronym for standardized tests of literacy related to health outcomes (e.g., WRAT, REALM, and TOFHLA). For MEDLINE®, our primary database, we had to rely on key word searches because no MeSH® headings specifically identify literacy-related articles. Other databases included the Cumulative Index to Nursing and Allied Health (CINAHL®), the Cochrane Library, the Educational Resources Information Center (ERIC), the Public Affairs Information Service (PAIS), and the Industrial and Labor Relations Review (ILRR). We reviewed Web-based bibliographies and sought inputs from our Technical Expert Advisory Group (TEAG) and external peer reviewers for articles that we may have missed.

Beginning with a yield of 3,015 articles, we retained 684 from a review of titles and abstracts. Following complete review of full articles, we determined that 73 articles were relevant to address our key questions and met our inclusion/exclusion criteria.

We graded the quality of individual articles using an approach based on domains and elements appropriate for intervention and observational studies:12 study population, intervention, comparability of subjects, literacy measurement, maintenance of comparable groups, outcome measurement, statistical analysis, and appropriate control of confounding;we also noted funding source (but did not include that information in any numeric score). We also rated the strength of overall evidence, for the two key questions separately, in three domains: quality of the research; quantity of studies, including number of studies and adequacy of the sample size; and consistency of findings.[12,13]

Results

Key Question 1: Relationship of Literacy to Various Outcomes and Disparities

We identified 44 articles addressing relationships between literacy and use of health care services, health outcomes, costs of health care, and disparities according to race, ethnicity, culture, or age. Study designs, data analysis, and presentation varied widely. The number of participants enrolled ranged from 34 to 3,260. Literacy was most often measured with the REALM (13 studies), TOFHLA or S-TOFHLA (11), or WRAT (6). Literacy levels used to compare study participants varied widely among studies. Most studies reported the unadjusted (bivariate) relationship between literacy and the outcome of interest; 28 adjusted for at least one covariate, chiefly age and education. The quality of articles reviewed for these key questions was fair to good. The overall strength of evidence ranged from II (studies of strong design but remaining uncertainty because of inconsistencies or concern about generalizability, bias, research design flaws, or adequate sample size, or consistent evidence from studies of weaker design) to III (the number of studies was too limited to rate the strength of the literature).

1a. Health Care Services. Six studies measured the relationship between literacy levels and knowledge of the use of health care services: mammography,[14] cervical cancer screening,[15] childhood health maintenance procedures and parental understanding of child diagnosis and medication,[16] emergency department discharge instructions,[17] "Heart Health Knowledge,"[18] and informed consent.[19] All but one[16] demonstrated a statistically significant association between higher literacy level and knowledge of matters relating to use of these health services.

In two studies that prospectively evaluated the risk of hospitalization according to literacy status, inadequate literacy (relative to adequate literacy) was significantly associated with increased risk of hospitalization.[20,21] In adjusted analyses, however, another study found no significant relationship between literacy and number of self-reported health care visits among subjects recruited from emergency rooms and walk-in clinics.[22]

Two studies dealt with the relationship between literacy levels and three measures of health promotion and disease prevention interventions (screening for sexually transmitted diseases, cancer screening, and immunizations).[23,24] In adjusted analyses, a reading level at or above the ninth grade was associated with a 10 percent increase in the probability of having a gonorrhea test in the past year.[23] Adjusted analyses of cervical and breast cancer screening rates indicated that women with inadequate literacy had significantly greater odds of never having had a Pap smear or no mammogram in the past 2 years.[24] An adjusted analysis showed that patients with inadequate literacy had significantly higher odds of not having had either an influenza or a pneumococcal immunization compared to patients with adequate literacy.[24]

1b. Health Outcomes. Ten studies used knowledge either as one of several outcomes or as the only outcome in regard to several behaviors or conditions: smoking,[25] contraception,[26] human immunodeficiency virus (HIV),[27-30] hypertension,[31] diabetes,[31] asthma,[32] and postoperative care.[33,34] In general, these studies found a positive, significant relationship between literacy level and participants' knowledge of these health issues.

Three studies evaluated the relationship between literacy and smoking.[25,35,36] In adjusted analyses, the largest study (n = 3,019) found a significant relationship between low literacy and various measures of smoking among adolescent boys and girls.[36] Low reading ability was significantly associated (unadjusted analyses) with smoking among adults waiting for child-related services in private and public clinics.[35] However, unadjusted rates of smoking among 600 pregnant women did not differ by literacy status.[25]

Two unadjusted cross-sectional studies found a positive, significant relationship between higher literacy and likelihood of breast-feeding.[35,37] Another study determined, in adjusted analyses, that patients with higher literacy had significantly better metered dose inhaler techniques than those of lower literacy.[32]

The odds of having misused alcohol were significantly higher among boys but not girls with lower literacy levels.[36] Two other studies dealt with child behaviors. In adjusted analyses, youth from low-income neighborhoods who were more than two grades behind expected reading level (Slosson Oral Reading Test) were more likely than others to carry a weapon including a gun, take a weapon to school, miss school because it was unsafe, and be in a physical fight that required medical treatment.[38] Reading ability was an independent predictor of teacher-reported problem behavior, even after adjustment for early problem behavior and family adversity, and was lower at higher levels of family adversity.[39]

Four studies evaluated the relationship between literacy and adherence to medical regimens or clinical trial protocols;[40-43] two found no significant relationship.[42,43] Regarding medication adherence, lower literacy was significantly associated with a greater odds of self-reported poor adherence among patients taking antiretrovirals for HIV infection.[41] A more rigorous study, however, found no relationship.[43]

Three studies assessed the relationship between literacy and diabetes outcomes.[31,44,45] Two found statistically significant associations: first, parents' scores on the National Adult Reading Test (NART) were correlated with glycemic control among their children;[44] second, in adjusted analyses, lower S-TOFHLA scores were related to worse glycosylated hemoglobin (HbA1c) levels and reports of retinopathy and cerebrovascular disease.[9] Neither of two studies identified an independent relationship between literacy and presence or control of hypertension.[31,46]

One research group reported on the relationship between literacy and control of HIV infection in three cross-sectional studies (about 60 percent of patients participated in all three studies).[27,29,47] Unadjusted analyses produced mixed results: better reading was associated with greater odds of undetectable viral load in two studies[27,29] (but not in a third[47]) and also greater odds of having a CD4 count greater than 300.[27]

Five studies evaluating the relationship between literacy and self-reported depression yielded mixed results.[18,47-50] Four found statistically significant associations between lower literacy and higher rates of depression in various patient populations: persons in a cardiovascular dietary education program,[18] mothers,[49] HIV-infected patients,[47] and persons with rheumatoid arthritis.[50] Adjusted analyses in the fifth, and largest, study, however, did not show a significant relationship between literacy and depression among Medicare managed care patients.[48] Another study found no significant relationship between literacy and "emotional balance" among patients receiving informed consent for a bone marrow transplant.[51]

Literacy was not associated with functional status among patients with rheumatoid arthritis,[50] presence of migraine headaches among children,[52] or presentation with late-stage prostate cancer (in adjusted analyses).[53]

Four cross-sectional studies evaluated the relationship between literacy and a global health status measure.[10,22,54,55] Two found a significant association between lower literacy and worse health status in adjusted analyses of adult patients,[22,54] and one found a similar association in unadjusted analyses of elderly patients.[10]

1c. Costs of Health Care. The one study of low literacy and health care costs reported no relationship between literacy and overall or component charges for Medicaid services among patients enrolled largely because of pregnancy rather than medical need or medical indigence.[56]

1d. Disparities in Health Outcomes or Health Care Service Use. One study directly examined the role of literacy as a mediator of disparities in health outcomes or health care service use.[53] In unadjusted analyses of data from a cross-sectional study of men with prostate cancer, black patients were significantly more likely than white patients to present with late-stage cancer; after adjusting for literacy, the researchers reported a smaller odds ratio that was no longer statistically significant.

Key Question 2: Interventions for People with Low Literacy

In all, 29 articles described interventions to mitigate the effects of low literacy on health outcomes, using randomized controlled trials, nonrandomized controlled trials, and uncontrolled, single-group "before-and-after" studies. The number of participants enrolled ranged from 28 to 1,744; most studies had between 100 and 500 participants. Of these 29 studies, 19 measured the literacy of each participant: REALM (10 studies), WRAT (4), and various other instruments (5);criteria to define literacy level categories varied across studies. The remaining 10 studies involved populations known from previous research or clinical assessment to have a large proportion of people with poor literacy skills. We characterized the general quality of these articles as fair. The overall strength of evidence was either III or IV (no study addressed the question).

2a. Health Care Services. The only article addressing question 2a concerned preventive services. In a nonrandomized controlled trial, an intervention consisting of a 12-minute video, coaching tool, verbal recommendation, and brochure significantly improved mammography utilization at 6 months (but not 24 months) compared with the verbal recommendation and brochure alone.[57]

2b. Health Outcomes. Most studies addressing health outcomes focused on improvements in knowledge. In most cases, participant knowledge improved after receiving the intervention. In five studies, investigators measured patient literacy and stratified the effect of the intervention by literacy status.

In a controlled trial among patients at a sleep apnea clinic, participants with low literacy appeared to display higher knowledge with a videotape educational tool than with a brochure written at a readability level similar to the videotape's script, but this conclusion is limited by methodological problems with multiple comparisons.[58] In another study, women of lower literacy understood illustrated materials about cervical cancer better than text materials.[59] In a randomized trial among cancer patients to examine the effect of an interactive videodisc to improve self-care of cancer fatigue symptoms, patients who received the intervention reported greater self-care ability, but this effect was not significantly related to the literacy level.[60] Another controlled trial compared a locally developed pamphlet about polio vaccine designed for patients with low literacy and a pamphlet from the Centers for Disease Control and Prevention that had also been designed for easy readability;[57] patients with lower literacy did not differ in their comprehension of the two pamphlets. Finally, a randomized trial of 1,100 patients compared the effectiveness of educational materials on colorectal cancer screening (videotape or easy-to-read brochure intended to be appropriate for people with low literacy) to usual care.[61] Patients receiving either intervention had significantly greater improvements in knowledge scores after reviewing the educational materials than did the control group; both low- and high-literacy groups that received either intervention showed significantly improved knowledge between the pre- and posttests, but rates of improvement in the two literacy groups did not differ significantly.

Several studies of the effect of interventions on health behaviors produced mixed results. Pregnant smokers and ex-smokers who received a specially designed intervention with materials written at the third grade reading level were more likely to achieve abstinence during pregnancy and 6 weeks postpartum than those who received standard materials; effects were greater among current smokers at entry than among ex-smokers.[62] A community-based osteoarthritis intervention improved exercise behavior in a 6-week, before-and-after uncontrolled trial.[63] Medication adherence among patients 65 years and older improved over time when they were given verbal teaching about medication compliance; adding a color-coded medication schedule did not provide additional benefit.[64] Interventions addressing dietary behaviors produced small or no changes.[65-68]

Several studies used changes in biochemical or biometric markers to test the effect of their interventions. Participants in a specially designed workplace hypertension education and behavior change program had modest differences in blood pressure levels compared with those for nonparticipating controls.[69] Special cardiovascular nutrition or dietary interventions did not achieve significant differences in postprogram cholesterol levels for low-literacy patients.[67,70] Finally, a randomized trial of a special educational intervention for patients with diabetes did not produce significant differences in HbA1c levels or weight loss.[71]

Few studies examined the effect of interventions on health outcomes that people can actually feel. An uncontrolled before-and-after trial found that an osteoarthritis education intervention could improve the functionality of people with osteoarthritis.[63] The only study to examine the effect of an intervention that included direct literacy-skill building demonstrated that a comprehensive family services center, compared with standard Head Start, could improve parental reading skill and reduce the prevalence of paternal depression.[72]

2c. Costs of Health Care. No study assessed costs, charges, or reimbursements for these types of interventions.

2d. Disparities in Health Outcomes or Health Care Service Use. No study evaluated the effect of literacy-related interventions in narrowing disparities according to race, ethnicity, culture, or age.

Discussion

General Conclusions

Our review includes material different from that in previous reviews of literature of health literacy; in addition, it excludes important articles because they did not address our two key questions. Earlier reviews reached conclusions similar to ours about the general relationship between literacy and health;[2,73] our rigorous approach should give readers confidence in the conclusion that low reading skill and poor health are clearly related. Conclusions about the effectiveness of interventions to mitigate the effects of low literacy remain less well supported at this time.

Future Research

Use of a wide variety of literacy measures and cutpoints for analysis and a wide range of outcomes made comparisons among studies difficult. Measurement techniques for low-literacy populations warrant additional development and refinement. Of special importance are investigating whether and how literacy affects self-report of use of health care or health outcomes and designing questionnaires that are valid and consistent across literacy levels.

One limitation of the knowledge base to date is lack of appropriate specification for analytic models when variables being considered as potential confounders actually mediate the effect of reading ability on important health outcomes. Future research can build on previous work by examining more closely and rigorously the factors that mediate this relationship. For example, investigators could examine whether poor reading ability is really the cause of adverse health outcomes or whether it is a marker for, say, low socioeconomic status, poor self-efficacy, low trust in medical providers, or impaired access to care. Such information is crucial to designing and testing intervention studies.

Current research is heavily weighted toward studies with limited or no longitudinal component. The predominance of cross-sectional study designs for studies of literacy and health relationships makes it impossible to measure incident outcomes or assign cause and effect. Thus, more prospective cohort studies that measure changes in outcomes and literacy over time will provide a greater understanding of the relationships among literacy, age, and health outcomes and the extent to which changes in health status actually affect literacy.

Intervention studies have focused mostly on short-term knowledge outcomes rather than on more meaningful health outcomes. Future studies could link these short-term knowledge changes to important health outcomes.

Moreover, many interventions involve multiple components, but use of multimodal interventions inhibits understanding of which portions produced positive effects. Analysis that isolates the individual effect of the key components could help determine "how much" intervention is enough to improve health. Documenting the importance of low patient literacy in chronic illness programs and understanding how to mitigate its effects are further important research avenues to foster understanding of how health system changes can positively affect literacy-related barriers.

Many interventional studies did not stratify outcomes by literacy level. Researchers should take this analytic step so that they can draw appropriate inferences about whether the intervention worked specifically among low-literacy individuals and helped to ameliorate differences in outcome according to literacy status. Studies could also determine whether measuring or stratifying outcomes by numeracy provides greater predictive ability for health outcomes than measuring and stratifying outcomes by literacy alone.

Investigators should compare interventions directed specifically at reducing literacy-related barriers with other means of improving health outcomes. Investigators in this field tend to focus on literacy as the variable of interest and, thus, often assume that improved written communication can improve health outcomes. Improving information delivery alone may, however, not mitigate the observed relationship between low literacy and poor health. Addressing self-efficacy, self-care, trust, or satisfaction may increase understanding of effective strategies for addressing poor health outcomes.

Provider-patient communication interventions that go beyond written materials may also prove to be a valuable avenue for future research. Investigations designed to teach physicians to use a "teach-back" method or other communication styles will aid understanding of whether and how they can improve outcomes.

Poor descriptions of interventions and lack of reporting how health outcomes were assessed, particularly whether questionnaires were presented in ways that would allow accurate responses by participants with limited literacy, hampered synthesis of this literature. Another drawback to the current literature is lack of use (or at least incomplete reporting) of appropriate statistical measures (e.g., use of P values without measures of magnitude or confidence intervals), which made it difficult to determine if null findings represent true lack of effect or limitations in power. Thus, reporting of study interventions, statistics, and results should be improved.

Finally, both the concept of health literacy and its role in health care use and health outcomes need further evaluation. The current literature focuses on reading ability and health;

taking a patient-centered approach that addresses challenges in navigating the health care system and providing self-care may enrich understanding of health literacy and ultimately how to measure and improve it.

Availability of the Full Report

The full evidence report from which this summary was taken was prepared for the Agency for Healthcare Research and Quality (AHRQ) by the RTI International–University of North Carolina Evidence-based Practice Center, under Contract No. 290-02-0016. It is expected to be available in February 2004. At that time, printed copies may be obtained free of charge from the AHRQ Publications Clearinghouse by calling 800-358-9295. Requesters should ask for Evidence Report/Technology Assessment No. 87, *Literacy and Health Outcomes*. In addition, Internet users will be able to access the report and this summary online through AHRQ's Web site at www.ahrq.gov.

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Hope for the Future:

Achieving the Original Intent of Advance Directives

by SUSAN E. HICKMAN, BERNARD J. HAMMES, ALVIN H. MOSS, AND SUSAN W. TOLLE

The development of new, life-prolonging medical technologies in the 1970s aroused concern among Americans about the indiscriminant use of aggressive, life-prolonging treatments. Highly public cases such as those of Karen Ann Quinlan and Nancy Cruzan drew attention to the importance of end of life care planning for healthy adults. Advance directives were developed as a way for people to retain control over their medical care by specifying their treatment values and choices and by naming someone to make medical decisions once they were no longer able to do so. Over the past several decades, it has become clear that statutory advance directives alone have not been as successful as originally hoped in giving patients control over their end of life care. However, the initial goal of advance directives was laudable and is worth preserving. Promising new models have evolved from practice and research that move us closer to achieving the original intent of advance directives.

Most traditional advance directives, such as statutory living wills and surrogate appointments, were created by legislative processes that set specific requirements about content and established rules regarding their use to define the rights of adults to forgo medical treatment, to protect providers who honor these decisions, and to appoint an authorized surrogate decision-maker. Statutory living wills are a tool for patients to express preferences about medical treatments that can be used if a person is no longer able to make his or her own decisions. These documents typically focus on potentially life-prolonging treatments in a very limited set of circumstances, such as when a person is faced with "imminent death regardless of treatment" or is in a "persistent vegetative state." In most states, a person can also designate a surrogate to make decisions in the event the patient loses decisional capacity. Depending on state law, a surrogate may be called a health care proxy or agent, medical power of attorney, or durable power of attorney for health care.

Limitations of Traditional Advance Directives

Despite the hope that traditional advance directives would ensure that patient preferences are honored, numerous studies have found that only a minority (20 to 30 percent) of American adults have an advance directive and that these documents have limited effects on treatment decisions near the end of life, though more recent research suggests use may be higher at the end of life. In addition to a low completion rate, there are many reasons why traditional advance directives are less successful than originally hoped. These reasons include the following:

> (1) The focus is often on a patient's legal right to refuse unwanted medical treatments, reflecting the legislative origins of traditional advance directives. Those who complete such documents generally do not receive assistance in understanding or discussing their underlying goals and values.
>
> (2) The instructions given in these documents and the scenarios provided for discussion are generally either too vague to be clear (for example, "If I am close to death") or too medically specific to be helpful in com-

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mon clinical situations (for example, “If I am in a persistent vegetative state”).

(3) Vague instructions result in conversations that produce equally vague expressions of wishes such as “Do not keep me alive with machines” or “Let me die if I am a vegetable.”

(4) Once advance directives are completed, planning is typically considered finished. A systematic effort to reopen the conversation as a person’s health declines is rarely made. The only repeated question that a patient might hear is, “Do you have an advance directive?” as required by the Patient Self-Determination Act.

(5) Traditional advance directives are seen as a right of the patient, with little attention given to routinely integrate planning into the clinical care of patients.

(6) Traditional advance directives are based on the assumption that autonomy is the primary mode of decision-making for most people. However, many people in the United States, particularly those from non-Western cultures, conceptualize the broader social network as the basis of treatment decisions, not the wishes and needs of the individual. Patients may also choose to delegate their autonomy to a family member, religious leader, or others, and defer discussions about prognosis and treatments for cultural or other reasons.

(7) In selecting a surrogate, a patient authorizes someone to speak on his or her behalf; however, advance directives typically do not include directions for the surrogate or health care professionals about treatment preferences unless special instructions are also provided. Additional information about values and goals is important to assist surrogates in decision-making during stressful times.

(8) Some patients may wish for their surrogates’ or families’ interests to be taken into account in decision-making rather than expecting the surrogate to base decisions solely on the wishes of the patient using a substituted judgment standard. Research suggests that many patients do not expect surrogates to rigidly follow their traditional advance directives, but rather intend for surrogates to exercise judgment to determine the course of care when there is insufficient information available or for extenuating circumstances.

In response to the difficulties with traditional legalistic advance directives, clinicians and researchers have developed new models that preserve the original goal of advance directives while addressing their shortcomings. One well-known example is “Five Wishes,” a document that incorporates a surrogate appointment with a range of wishes about medical, personal, spiritual, and emotional needs (www.agingwithdignity.org). Five Wishes offers advantages over traditional advance directives because it covers a range of issues typically not found in statutory living wills or health care power of attorney documents, such as how comfortable a person wants to be or how he or she wishes to be treated if unable to speak for him or herself. Five Wishes meets the legal requirements for advance directives in thirty-seven states and the District of Columbia. Unfortunately, there are no published research studies to support the efficacy of Five Wishes in guiding surrogates and health care professionals or in ensuring that wishes are honored.

“Let Me Decide” is a recently developed Canadian program with empirical data to support its effectiveness (www.newgrangepress.com) The program was studied in a randomized, controlled trial of 1,292 residents at a group of regional nursing homes and hospitals in Ontario. Residents and their family members had an opportunity to document a range of health care choices regarding levels of care, nutritional support, and cardiopulmonary resuscitation. The program was implemented systematically and nursing home staff received training in how to integrate the advance directive into clinical care. Results indicate that the intervention group had a higher prevalence of planning. Additionally, plans were more specific, residents were less likely to die in the hospital, fewer resources were used, and families were more satisfied with the process than were family members in the control facilities using more traditional advance care planning.[1]

In La Crosse, Wisconsin, “Respecting Choices” began in 1991 as part of a community-wide care planning system (www.gundersenlutheran.com/eolprograms). Local health care systems developed institutional policies to ensure that written advance directives were always available in their medical records when needed. Components of the program include staff education about the program and advance care planning; clearly defined roles and expectations of physicians; training for advanced care planning facilitators; routine public and patient engagement in advanced care planning; clinically relevant advance directives incorporated into clinical care; and written protocols so that emergency personnel can follow physician orders that reflect patient preferences. Quality improvement projects were undertaken to measure outcomes and to improve parts of the system when they did not perform in the way intended.[2]

A study of the Respecting Choices program evaluated La Crosse County deaths over an eleven-month period (524 in all). Eighty-five percent of all decedents had some type of a written advance directive at the time of death; 96

percent of written plans were found in the medical record where the person died; and treatment decisions made in the last weeks of life were consistent with written instructions in 98 percent of the deaths where an advance directive existed. Decedents with written advance directives were also significantly less likely to die in the hospital (31 percent versus 68 percent, p=0.001). Respecting Choices is now being implemented by more than fifty-five communities and organizations in the United States and Canada and is being piloted nationwide in Australia.

One of the most studied systems of advance care planning and documentation is the "Physician Orders for Life-Sustaining Treatment" paradigm, originally developed in Oregon (www.polst.org) and complementary to Respecting Choices (in fact, the Respecting Choices program strongly advocates use of the POLST paradigm to document physician orders in the out-of-hospital setting). The POLST form is designed for patients with serious illness and advanced frailty. The centerpiece of the program is the POLST document, a brightly colored medical order form that converts patient treatment preferences into written medical orders based on a conversation among health care professionals, the patient, and/or surrogates about treatment goals (see figure 1). The form transfers with patients across care settings to ensure that wishes are honored throughout the health care system. The POLST form is an example of an actionable advance directive that is specific and effective immediately. In a prospective study at eight nursing homes, residents whose POLST forms included a do not resuscitate (DNR) order and an order for comfort measures only were followed for one year. None received unwanted intensive care, ventilator support, or cardiopulmonary resuscitation.[3]

In contrast to the varied out-of-hospital DNR orders used around the country, the POLST paradigm provides patients the opportunity to document treatment goals and preferences for interventions across a range of treatment options, permitting greater individualization.[4] Research suggests that the POLST form accurately represents patient treatment preferences the majority of the time[5] and that treatments at the end of life tend to match orders.[6] A majority of nursing homes and hospices in Oregon use the voluntary POLST Program, and POLST is widely recognized by emergency medical services.[7] At least thirteen states have adapted versions of the POLST program, including Oregon, Washington, West Virginia, Utah, and parts of Wisconsin, New York, Pennsylvania, North Carolina, New Hampshire, Tennessee, and Michigan, reflecting a high degree of acceptance by health care professionals. Each state has made minor alterations to the document to accommodate local regulations and statutes. A National POLST Paradigm Task Force formed in 2004 to support national growth of the program.

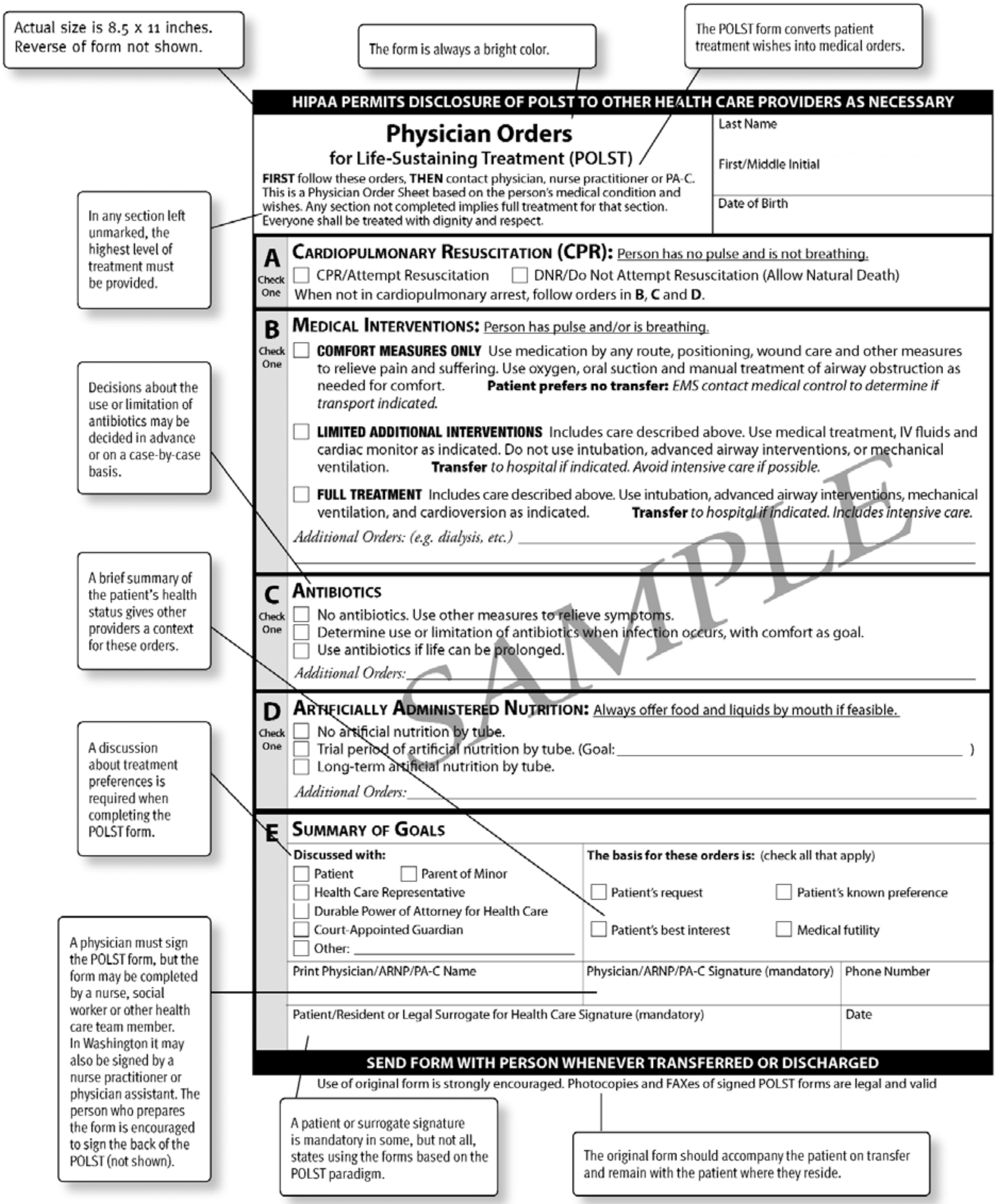
Elements of Successful Advance Directive Programs

The newer, more successful, clinically based advance directive programs share key elements: a facilitated process, documentation, proactive but appropriately staged timing, and the development of systems and processes that ensure planning occurs.

First, successful advance directive programs are not limited to the content or rules relating to legal documents. Instead, an individualized plan is developed through a process of interaction with the patient that is specific not only to the patient's values and goals, but also to his or her relationships, culture, and medical condition. Advance care planning should focus on defining "good" care for each patient, rather than on simply listing the right to refuse treatment or promoting individual autonomy. A skilled facilitator can enhance advance care planning by engaging those who are close to the patient so that they understand, support, and follow the plans that are made. The process permits shared or delegated decision-making depending on the beliefs and preferences of the patient. Facilitators should encourage patients and surrogates to discuss how much leeway a surrogate has in decision-making.

Second, for advance directive programs to be implemented successfully as a patient moves between different treatment settings, documentation of wishes, goals, and plans is essential. This documentation should include the identity of a designated surrogate. Ideally, this documentation would be in the form of actionable advance directives that direct treatment with specific medical orders reflecting a patient's current treatment preferences—in contrast to traditional advance directives that address preferences in hypothetical future scenarios. To be truly effective, the actionable advance directive form must be standardized and recognized throughout the broader health care system, and it must provide clear, specific language that is actionable in all settings to which a patient might be transferred. The power of actionable advance directives is most completely realized in a system in which all institutional entities that interact with the patient (health care personnel in emergency medical services, emergency departments, hospitals, nursing homes, hospices, home health care, and others) recognize the actionable advance directive form and are authorized to follow its written orders.

Third, successful advance directive programs also require proactive but appropriately staged timing: some discussion should anticipate health care decisions, but much of it must be revisited as the patient's prognosis becomes known. For an otherwise healthy patient, the presumption is that the treatment goal is to return to his or her prior state of health. Individuals who fit this description do not need an advance directive to guide initial treatment. However, healthy adults can benefit from the process of advance care planning to prepare for sudden, severe illness or injury. Healthy adults should appoint a trusted family member or friend to serve as a health care surrogate who can act as a strong advocate in the event that they are unable to speak for themselves. Healthy adults should also discuss with their surrogates whether and when a permanent loss of neurological function would be so bad that the goals of medical care would change from prolonging life to providing comfort, and



Actual size is 8.5 x 11 inches. Reverse of form not shown.

The form is always a bright color.

The POLST form converts patient treatment wishes into medical orders.

In any section left unmarked, the highest level of treatment must be provided.

Decisions about the use or limitation of antibiotics may be decided in advance or on a case-by-case basis.

A brief summary of the patient's health status gives other providers a context for these orders.

A discussion about treatment preferences is required when completing the POLST form.

A physician must sign the POLST form, but the form may be completed by a nurse, social worker or other health care team member. In Washington it may also be signed by a nurse practitioner or physician assistant. The person who prepares the form is encouraged to sign the back of the POLST (not shown).

A patient or surrogate signature is mandatory in some, but not all, states using the forms based on the POLST paradigm.

The original form should accompany the patient on transfer and remain with the patient where they reside.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders
for Life-Sustaining Treatment (POLST)

FIRST follow these orders, **THEN** contact physician, nurse practitioner or PA-C. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name

First/Middle Initial

Date of Birth

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** Person has no pulse and is not breathing.

☐ CPR/Attempt Resuscitation ☐ DNR/Do Not Attempt Resuscitation (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in **B**, **C** and **D**.

B Check One — **MEDICAL INTERVENTIONS:** Person has pulse and/or is breathing.

☐ **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Patient prefers no transfer:** *EMS contact medical control to determine if transport indicated.*

☐ **LIMITED ADDITIONAL INTERVENTIONS** Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. **Transfer** *to hospital if indicated. Avoid intensive care if possible.*

☐ **FULL TREATMENT** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer** *to hospital if indicated. Includes intensive care.*

Additional Orders: (e.g. dialysis, etc.) ____________________

C Check One — **ANTIBIOTICS**

☐ No antibiotics. Use other measures to relieve symptoms.
☐ Determine use or limitation of antibiotics when infection occurs, with comfort as goal.
☐ Use antibiotics if life can be prolonged.

Additional Orders: ____________________

D Check One — **ARTIFICIALLY ADMINISTERED NUTRITION:** Always offer food and liquids by mouth if feasible.

☐ No artificial nutrition by tube.
☐ Trial period of artificial nutrition by tube. (Goal: ____________________)
☐ Long-term artificial nutrition by tube.

Additional Orders: ____________________

E — **SUMMARY OF GOALS**

Discussed with:
☐ Patient ☐ Parent of Minor
☐ Health Care Representative
☐ Durable Power of Attorney for Health Care
☐ Court-Appointed Guardian
☐ Other: ____________________

The basis for these orders is: (check all that apply)
☐ Patient's request ☐ Patient's known preference
☐ Patient's best interest ☐ Medical futility

Print Physician/ARNP/PA-C Name	Physician/ARNP/PA-C Signature (mandatory)	Phone Number
Patient/Resident or Legal Surrogate for Health Care Signature (mandatory)		Date

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid

Figure 1. Sample POLST Form from Washington State

they should address the degree of leeway that they grant to the surrogate.

In people with advanced chronic disease and frailty, planning should expand to include discussion of changing treatment goals. Success rates for interventions decline as disease and frailty progress, and patients' evaluations of the desirability of interventions often change in the face of this new reality. Patients and families look to health care professionals to initiate conversations about end of life care planning, and it seems most relevant to broach the topic in the context of a limited prognosis. Once the prognosis has been discussed, health care professionals (but not necessarily physicians) trained to facilitate advance care planning discussions can help guide patients so that plans are specific not only to the patient's experiences, values, and goals, but also to the patient's health condition, culture, and personal relationships. This planning should focus on treatment goals in scenarios likely to occur in the course of that person's chronic disease. Completion of an actionable advance directive may be particularly helpful at this time.

Finally, perhaps the most crucial elements of more successful advance directive programs are policies, procedures, and teamwork within each part of the health care system that ensures advance care planning and implementation occurs. Plans need to be clear and should reflect the individual's values and goals. Plans should be updated over time and available when needed; whenever possible, plans should be honored. A successful model requires the establishment of systems at many levels to achieve these goals. Health care organizations can create policies and procedures to assure that any written plan is available when needed. The roles and responsibilities of different health professionals must be clearly defined so that each person knows his or her part and can perform it. Furthermore, optimal performance of each player's role benefits from periodic assessment, which requires that health organizations conduct quality improvement initiatives to ensure that the implemented system achieves the desired outcomes. Organizations should be prepared to gather the necessary information to improve the system when and where it falls short.

For advance directives to be effective, they need to be integrated into each part of the system of care, including emergency medical service protocols and regulations. State statutes vary regarding traditional advance directives, surrogate appointment, and other relevant factors, such as emergency medical technicians' scope of practice. Therefore, state end of life coalitions consisting of key stakeholders (emergency medicine, long-term care, hospice, nurses, physicians, and health lawyers, among others) may need to identify and overcome state-specific regulatory, legal, and cultural barriers to the implementation of optimal advance care planning.

The original intent of advance directives to enable patients to retain control over their terminal care once they lose decision-making capacity was not fully achieved through the use of the traditional advance directives. New, more successful models address the limitations of the traditional models yet remain true to the concept's original intent. The key elements of these new models are advance care planning in a system with specially trained personnel; highly visible, standardized order forms that are immediately actionable; proactive, appropriately staged timing; ongoing evaluation and quality improvement.

For these new models to be used more broadly, systems to implement them will need to be established in each state and within every health organization. These systems need to ensure that traditional and actionable advance directives are written at the appropriate time, that they are recognized, and that they are honored. Given the initial success of these models, it is reasonable to believe that the original goal of advance directives—to ensure respect for patients' treatment wishes at the end of life—can and will be more completely realized in the future.

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EPEC

Education for **P**hysicians on **E**nd-of-life **C**are

Participant's Handbook

Plenary 3

Elements and Models of End-of-life Care

Emanuel LL, von Gunten CF, Ferris FD. The Education for Physicians on End-of-life Care (EPEC) curriculum, 1999.

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Abstract

The public expects the relief of human suffering to be a significant goal of the medical profession. Suffering can be conceptualized as a fragmentation of personhood, as a disturbed life story, as an opportunity, or as total pain. Patients don't suffer in isolation; patients and families must be considered together. Suffering is best relieved by using a team to approach the many elements involved in end-of-life care. The health care system that acknowledges those characteristics of the individual patient/family that cannot be changed and intervenes to influence those characteristics that can be changed will be able to deliver the best possible outcome. The phrase *palliative care* defines a model for the relief of suffering and the improvement of quality of life across the spectrum of illness. Hospice is currently the most widely available program for the delivery of palliative care at the end of life.

Key words

communities, continuum of care, culture, economic burdens, ethnicity, family and friends, fixed elements, framework, health care systems, hopes, hospice, institutional change, meaning, modifiable elements, outcomes, palliative care, personhood, physical symptoms, psychological, race, social, socioeconomic status, spiritual, standards, story, suffering, total pain

Objectives

The objectives of this plenary are to:

- describe conceptions of suffering
- describe the elements of end-of-life care
- define palliative care
- describe hospice and palliative care program standards

Introduction

Experiences toward the end of life are so closely associated in peoples' minds with suffering that it is hard to use one term without assuming the meaning of both. The aim of quality end-of-life care is, however, to avoid needless suffering in order to permit experiences that will have positive meaning. For this to happen, it is necessary for everyone involved to understand something about suffering, other elements of experience when facing the end of life, the types of intervention that can be helpful, and the resources and teamwork it takes to make these interventions available.

As Eric Cassell has written so persuasively, the public imagines that we as a medical profession study the issue of suffering in medical school. Indeed, they expect us to be experts at the relief of suffering. As he pointed out in a remarkable paper published in 1982, the public would be shocked to learn that this subject doesn't get much attention in medical training. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relieve suffering have been neglected in the training of physicians.

Organizing these concepts of suffering, connecting them with a framework for understanding the elements involved in end-of-life care, and with models for palliative care delivery systems, all in one coherent whole, is the task of this plenary session.

Conceptions of suffering

What does it mean to suffer? As a medical profession, and as part of a health care system, we must have a conceptual framework within which to work, study, and teach if we are to have a hope of relieving suffering. This is similar to other aspects of medicine—for each disease, each condition for which human beings seek assistance from the health care professions, there is a conceptual framework to investigate, understand, and intervene.

In an attempt to understand suffering in a way that would permit further study and understanding and inform clinical care, Cassell outlined a conceptual framework for suffering. He pointed out that "bodies do not suffer, only persons do." Persons are unique and do not experience a disease in the same way. Persons suffer when their personhood is threatened. Elements of what it means to be a person include having a past, a present, an anticipated future, a private life, a role, and a transcendent dimension.

Brody has built on the concept that personhood requires a past, present, and future by noting that human lives are, in a sense, stories. Our story is our sense of self, and as we face dying, our story comes to closure. In so doing our story transforms into our legacy. So often, when the patient comes to a physician, the emotional subtext of the patient's complaint can be heard as, "Doctor, my story is broken. Can you fix it?" Much suffering by patients facing the end of life can be understood in this perspective. The future looks different from before, and the present is consumed with new physical degeneration. The patient's private life is challenged by many new transitions, as is his or her usual role. The transcendent dimension may take on a new meaning.

Suffering is a challenge to meaning. Facing the end of life may challenge our usual sources of meaning. Loss of meaning is a form of suffering. Meaning usually must be found in new ways when death approaches. As you consider what you would list as the things that give you the most meaning and value in your life, think about how the prospect of disease might affect those. Byock has described the nature of opportunity brought by suffering and facing the end of life.

These same aspects apply to a child who is dying. In addition to the suffering of the child who is seriously ill, the parents and siblings suffer as they face the loss of this child, and their shared sense of the future.

However, the experience of illness and suffering is not unique to each individual. In listening to patients with advanced illness describe their needs and expectations for care, Cicely Saunders, founder of the modern hospice movement, conceptualized suffering as having 4 elements. She termed it “total pain” and identified the elements of physical, psychological (emotional), social (including practical), and spiritual pain. As you reflect on the things that you value most, and those that would be most important to you in the face of a life-threatening illness, most of them probably fit into these 4 categories.

The broad perspective

All of these conceptions have 1 thing in common; they take a very broad perspective from which to view human existence. As health care providers, it is important that we have a comprehensive framework from which to work if we are to relieve suffering and enhance quality of life. Well-intentioned efforts that are too narrow in scope will miss the target. A narrow focus on physical pain can miss the patient who is depressed, or doesn’t have the money for the pain medicines, or is afraid that the pain means that she is going to die. Yet, all of these aspects of human experience will influence the experience of pain. Similarly, a patient whose spiritual foundation is not challenged is less likely to complain about physical symptoms, while failure to address the spiritual dimension in a patient who is spiritually distressed may distort the physical dimension. As another example, a patient who feels abandoned by family, community, or medical professionals may express his or her suffering by emphasizing a physical complaint, or by giving up hope. While each aspect of human existence is an integral part of who we are, undue focus on any one aspect may be detrimental (eg, undue focus on a patient’s social disconnection may distract a clinician from attending to physical needs).

Based on the conceptions of suffering discussed above and a commitment to the broad perspective of human existence, this plenary will consider the elements of the health care system that may be able to relieve suffering and enhance quality of life.

Elements of end-of-life experience

Elements in the broad conceptualization of end-of-life experience can be thought of in 4 categories: fixed elements, modifiable elements, interventions, and outcomes. Some of what the patient brings with himself or herself cannot change; in fact it would not be desirable to change some aspects. Knowing and accommodating these fixed characteristics, the clinician may then focus on a person’s modifiable dimensions. Then the task is to identify the patient’s expectations and needs, and deliver the appropriate care interventions, whether directly by the clinician or through other aspects of the system. Together these elements of need and care combine to determine the overall experience of the dying process—the outcomes by which the health care system and society must measure our performance.

Fixed characteristics of the patient

The most prominent fixed characteristic of a patient facing the end of life is his or her disease and its prognosis. Other fixed features have to do with the patient's background. Issues that arise as a person faces the end of his or her life, or as people face the loss of a loved one, are handled differently by people depending on their background and experience of life, ie, race, ethnicity, culture, religion, socioeconomic class, etc.

Some physicians may have competence in the care of patients with particular cultural backgrounds. Others may not. In any case, the individual patient's background must be learned. Through respectful inquiry, the physician can quickly learn about the patient's specific cultural issues.

Race

An individual's background can be broadly categorized into differences of race, ethnicity and culture, religion, and socioeconomic class. There are many ways in which these differences combine—race may not track culture, culture may not track religion, socioeconomic class may not track ethnicity, and so forth. Nonetheless, the categories provide a framework from which to work through the issues for an individual patient.

As examples, several studies have demonstrated race-related differences in preferences for life-prolonging intervention toward the end of life. Commentators have raised the possibility of mistrust across racial difference. In conducting advance care planning discussions or establishing goals for care, sensitivity to the possibility of mistrust may be helpful.

Ethnicity and culture

The impact of illness is handled differently in different ethnic and cultural groups. Culture has been shown to be a strong determinant in attitudes toward end-of-life decisions and care. A good deal of useful information is available on various cultural attitudes toward health, illness, and dying. However, it is important to remember that people are individuals and the best way to understand another person's culture is to listen carefully to his or her values and beliefs. Open, balanced communication is what is required to negotiate cultural differences.

Respect can be conveyed by erring on the formal side of normal interactions, at least to begin with. It is important to remember that our current-day norms in the US of informality are in the minority among cultural approaches. If questions are respectfully posed they will rarely be offensive.

It is always best to use interpreters when language barriers exist; using family members is fraught with difficulty. If there is a translator, you can also learn from him or her if someone is available and knowledgeable in the relevant group's context for living.

Further considerations are treated in various modules, including issues of information and truth telling, maintaining reasonable hope (see Module 7: Goals of Care), and involvement of translators (see Module 2: Communicating Bad News).

Modifiable dimensions

While the patient comes to the physician with an unchangeable diagnosis and a background that is set, there are often aspects of a patient's experience that are more modifiable than may be apparent initially. Physical symptoms, psychological and cognitive symptoms, social relationships and support, economic demands and caregiving needs, hopes and expectations, and spiritual, cultural, and existential beliefs can all change with time and effort.

Pain and other physical discomfort

Patients may experience many physical symptoms as a result of their serious and life-threatening illness. Pain, although exceedingly important, is not the only one. Fatigue, drowsiness, insomnia, dyspnea, anorexia, and nausea are but a few of the common symptoms suffered by patients. For pain, and most of these symptoms, there are validated assessment tools and effective treatments.

While research is still necessary to improve our ability to manage symptoms effectively, the biggest need is timely application of knowledge that is already available. Clinician assessment of a full range of possible symptoms, use of assessment tools, appropriate interventions, and outcome measures are now incumbent on the medical profession.

Psychological and cognitive symptoms

Depression is widely underrecognized and undertreated in the general patient population and is an especially important problem in the dying patient. Too many clinicians rationalize helplessness and hopelessness in their patients with the thought that it is natural to be depressed when dying. On the contrary, depression is a frequently treatable complication of life-threatening illness. Feeling miserable is not an inevitable part of dying. Clinicians should be vigilant and skilled in its treatment. Anxiety is another common form of emotional suffering. It is capable of exacerbating other forms of suffering and it is also treatable. Confusion, whether due to the illness or to treatment side effect, is also common and can range from minor degrees of disorientation to major and distressing hallucination. Mental suffering is as vexing as physical suffering. For some patients it is perhaps more so. Its recognition by the physician, assessment, and treatment are an integral part of end-of-life care.

Social relationships and support

Social relationships are usually challenged and changed by illness. A person's ability to stay in his or her job or go to school, to fulfill his or her prior role in the family, to keep up friendships, and to be active in the community are all undermined. Social attitudes to illness may isolate a person, and the burdens of care may lead to stresses in intimate relationships. Fear as well as anticipatory bereavement can occur in both the patient and those around the patient, and can cause changes in the orientation of relationships. All these challenges arrive at a time when the patient and family need extra support. Effective social support will be much more likely with some professional assistance. The discipline of social work is that group of health care professionals who have gained experience in the study of family and social relationships and understand how to assess and intervene. Use them as colleagues in the service of the relief of social suffering. It is a sad situation that, in too many places, social work as a discipline has diminished to be little more than discharge planning and insurance verification. While there are many forces at work, one of them is the silence of physicians, in part because they have not learned the framework of care in which social work plays such an important part in the relief of human suffering. Insist on good social work where you work.

The discipline of Child Life is that group of health care professionals who are educated and trained in communication with children at a level appropriate for that child's developmental stage. They are able to help identify a child's fears and desires, and what they do and do not understand about their illness, or the illness of their loved one. Many health care systems and physicians do not have a good working knowledge of the contribution that child life specialists can make in communicating with and helping dying children, as well as the child siblings of a dying child. Insist on child life staff in the program where you work.

Economic demands and caregiving needs

The personal and economic burdens associated with a life-threatening illness can be enormous. About one third of families report a significant loss of income and savings when there is a member of the family who is sick. Usually the wife or mother or daughter of the patient provides the care. Many people have to leave their paid work to do so. Women and single people have to pay for help more often than others. Financial losses are also incurred by insufficient insurance coverage or delayed reimbursement for services. Recognition of, acknowledgment of, and assistance with these burdens, usually by involving social service support professionals, are critical. You don't have to do the work yourself—insist on the assistance of the health care colleagues who are available to you. Involve the community if you can.

Hopes and expectations

A patient's or family member's outlook is greatly affected by his or her expectations. A traditional inclination to sustain a patient's or family member's hope even at the price of deception has existed at various times in the history of the profession. Further, there has been an assumption in recent years that only cure can bring hope.

Yet, in numerous studies, the American public is quite clear that the vast majority expect the physician to tell them the truth. In fact, there is positive work to be done in facing dying, and there are developmental goals to be realistically hoped for in finishing and reviewing life's achievements and in reaching closure well. Through observation and study, we have learned that hope can be maintained, or strengthened, when we render a candid opinion to the patient of his or her prognosis. The task of the clinician is to assist the patient and family in discerning and achieving their own realistic goals. This skill can be learned, just like the skills of physical diagnosis or surgery. Think in terms of the final stage of development and closure; expect that a patient's hope can be maintained, even in the face of dying. This concept is perceived to be more difficult for pediatric or young adult patients when the person is dying far before the "normal" time. However, the concept that the truth is needed is especially true for parents facing the death of their child or for young adults if appropriate decisions are to be made.

The specific focus of hope often changes over the course of the illness. In general, patients (and parents) can find fulfillment and closure in 4 ways. They can find meaning in understanding their achievements. A sense of readiness can come from having a chance to bring closure to their life. Comfort can be found in understanding that death is a natural part of the grand scheme of life, and in the hope of legacies left or connection with something that will live on after they are gone. For parents whose child is dying, comfort may be found in creating memories. The child's legacy can become the many lives affected by the child. Sometimes life's work can be completed within the span even of infancy. Security can be found in realizing the strength of their spiritual lives.

Spiritual, cultural, and existential beliefs

Chaplaincy is another important discipline that can support the patient, family, and physician in the relief of suffering. As with social work, most physicians have not been exposed to a framework for health care that properly includes this dimension and clinical specialty. The study and basis for clinical intervention in the spiritual dimension of illness and suffering is the primary work of chaplains. Some patients will do better without a pastor—if the physician simply frees them from their physical suffering so that they can get on with their own work. Other patients appreciate the pastor's support. Many clinicians have pastoral care professionals who can be included in a patient's team of care. Another approach is to involve the patient's own pastor. But be careful; involvement in a religious denomination does not necessarily enable a pastor to engage successfully in the relief of spiritual suffering any more than attendance in medical school gives you the ability to perform cardiothoracic surgery. Study, interest, practice, and facility are what make a good chaplain—as is true for a good surgeon. While medical professionals need not involve themselves directly in a patient's spiritual life, it is a critical aspect of life in advanced illness. Therefore, insist on competent chaplaincy in the settings where you work. Your patients deserve nothing less. Clinicians must be able to assess the importance of this sphere of life and help to engineer a plan that will address this unique aspect of human experience when it is appropriate—it is much easier with skilled colleagues working with you.

Health system interventions

Technical interventions have been the main focus of much of medicine. In this larger perspective it is clear that technical intervention is just 1 of many elements in end-of-life care. Furthermore, it is not all provided by physicians and other professionals. Far from it. Family and friends provide much support, and the community is another important possible source of care. Institutions can provide many sources of care.

Family and friends

The "front line" of care has always been provided by family and friends for a great majority of patients. Even in an age when many patients die in an institution, this is still true. Currently, care is moving back into the home, which is where 9 out of 10 patients want to be, and health care delivery systems now favor this as well. Clinicians who understand and encourage helpful family involvement in patient care can bolster and be assisted by rather than feel interrupted by and undermine this important source of care. In addition, the clinician who is aware of the burdens of care, and can direct the caregiver to a source of support, will help foster quality of life for patients and families.

Communities

Some patients are involved in communities that can provide spiritual activities, support groups, and even volunteer nursing-aide care. Other members of the health care team may know about more resources than you do—ask them. These resources can be invaluable and the clinician should welcome them in whatever way best supports the patient. A few calls from yourself or a member of your team to the patient's religious institution, school, workplace, or neighborhood community can put a network of care in place. One willing coordinator of community volunteers can provide transportation, help with shopping and home chores, or a few friendly visitors.

Professionals

The medical professional can uniquely guide and provide sources of care for suffering in all 4 elements of physical, psychological, social, and existential experience. The importance of interdisciplinary teams for this care cannot be overstated.

Technical interventions are the unique province of clinicians, and their importance is great. Clinicians should not lose track of the fact that some interventions do not involve adding on a treatment but rather withholding or withdrawing an unwanted or a no-longer-wanted intervention. In addition, clinicians must always recall the fact that empathic communication can itself be an intervention.

Societal institutions

Institutions in society powerfully determine peoples' activities and experiences as well as outcomes of those activities. This is no less true in end-of-life care. For instance, Medicare policies on hospice care determine who may receive what services in many cases.

Private institutions may also be influential in a patient's experience toward the end of life, whether these institutions are disease-based advocacy or support groups or community churches.

The nature of health care delivery systems greatly determines the possibilities for care, and this is taken up in the next major section.

Outcomes

Now, let's consider outcomes. There are both objective and subjective measures that are important in assessing the overall quality of care for dying patients and their families.

Objective measures

Objective measures include documentable portions of care such as physician's orders that evidence proper planning and care. Scales of symptom intensity should be used and can be correlated with treatment approaches to assess quality of care. Quality-of-life scales should be used as well. Global scales of suffering and of quality end-of-life care are being developed to provide clinically useful indicators as well as outcome measures. Scales for institutional processes of care are also under development.

Satisfaction

Subjective experience remains one of the most important outcomes in the end. Although surveys of satisfaction often show poor correlation with other indicators of quality care, it remains an important concept and a tangible outcome measure. In the end it is the subjective experience of dying, caring, and bereavement that are critical. Much of the fear, trepidation, and distrust of contemporary health care comes from direct experiences with a beloved family member or friend. We have the ability to alter this perception.

Models for care

We have defined suffering and built a conceptual framework for its relief and for the enhancement of quality of life. Nevertheless, health care institutions are critically important to our system of care. It is now widely recognized that cognitive information such as that covered in this EPEC curriculum is necessary, but not sufficient, to deliver good end-of-life care to our patients. Pernicious and sometimes perverse systems of care have developed that reinforce the status quo. Our current systems of health care were not conceived within a comprehensive framework for relieving suffering. As different studies have demonstrated, current systems may, in fact, promote suffering, particularly for those who are near the end of life.

Consequently, clinicians must often be creative in meeting the broad needs of their dying patients. Because physicians remain a key advocate for patients and their families within the health care system, you may be an agent for change within the health care systems in which you work. Urge yourself and your colleagues to insist on these elements for your patients. It is what you will want for yourself and your family when you need care.

An approach is developed in Plenary 4: Next Steps for fostering health care systems that work well for dying patients. To prepare for this, it is important to understand the concept of hospice and palliative care.

Hospice

In the 19th century, hospice was a term to describe places where the dying could be cared for. They were generally run by religious orders. In a remarkable development from listening to first 1 patient, then many patients, Cicely Saunders founded St Christopher's Hospice south of London, England, as a new kind of hospice. It is a place where a team of professionals in a single institution pursues the medical, emotional, social, and spiritual care of patients and families. Most importantly, it is an academic hospice, where education and research are pursued simultaneously with patient care. What we now generally term *palliative care* has grown out of, and includes, hospice care.

In the short 30 years since the founding of St Christopher's, what has been called the hospice movement developed on the fringes of institutional medicine. The response from institutional medicine was perhaps understandable—no conventional system likes to be challenged by a "movement" that is critical of the mainstream. Nevertheless, in the US, it has developed widely, primarily as programs of care for patients at home. The Health Care Financing Administration (HCFA) reported in 1994 that there were 1682 Medicare-certified US hospices serving nearly 20% of patients dying in the US. Many more have sprung up since then. The fruits of this movement are receiving considerable and well-deserved recognition.

In the United States, the single word *hospice* is used to describe 4 different concepts. Hospice can be a site of care for the dying, such as a free-standing facility or a dedicated unit within a hospital or nursing home. It can be an organization that provides care in a variety of settings but usually focused on the patient's home. The term is also used to describe an approach to care that is integrated into all manner of care sites and practices, including intensive care units if necessary. In this sense it is synonymous with palliative care. Finally, it is used to describe a benefit available to Medicare beneficiaries and subject to the rules and regulations promulgated by HCFA to govern that federal program.

Unfortunately, the use of a single term for all of these meanings has led to some confusion. For many patients, the term still means a place to go to die. For many physicians, the term *hospice* means a poorly understood community-based program into which a patient disappears after the physician signs a form certifying a prognosis of less than 6 months. These persist even though the majority of patients enrolled in hospice programs live in their own homes until they die, because that is where they want to die. Surveys of the American public indicate that, if they knew they had a life-threatening illness, more than 80% want to die at home.

It is incumbent upon all physicians to understand the concepts, as well as the details, so that their patients get the best possible care. Just as physicians work with their local hospitals, nursing homes, and other sites where health care is delivered, so physicians need to understand and work with their local hospice agencies so that the best possible care is administered.

Palliative care

To move beyond the confusion, the stigmatization, and the restrictions that have evolved as unintended consequences of the Medicare hospice benefit, the concept of palliative care has started to evolve as a response to the continued deficits in caring for patients and families. Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions has in common the focus on relieving suffering and improving quality of life. All of the definitions stress 2 important features: the multifaceted, multidimensional nature of the experience of living with an acknowledged time-limiting illness, and the priority of working as a team to achieve the relief of suffering and facilitate the enhancement of life. The importance of supporting the family and patient as a unit is clear. An issue that continues to be debated has been whether the term *palliative care* should refer to a discrete period at the end of life, or whether it is a concept that is relevant wherever suffering accompanies illness.

The Institute of Medicine defines palliative care in this fashion:

"Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure…. Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs…. It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them."

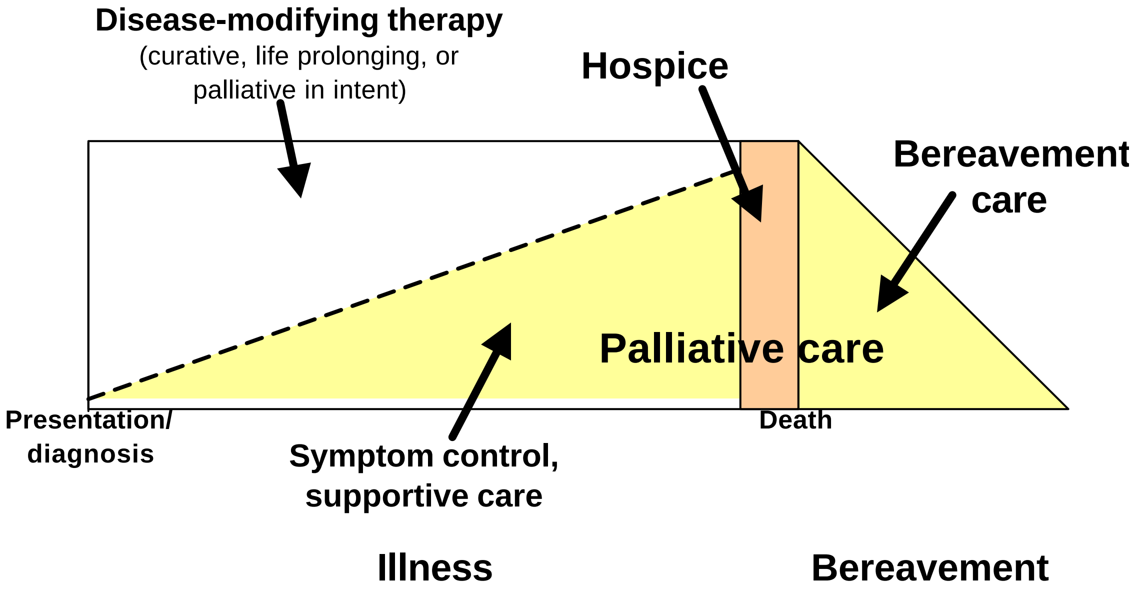
The World Health Organization (WHO) defines palliative care as:

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment."

It goes on to expand and explain with these 6 points:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates the psychological and spiritual aspects of care, fostering opportunities to grow
- offers an interdisciplinary team to help patients live as actively as possible until death
- offers a support system for the family during the patient's illness and their own bereavement

Continuum of care



Some have depicted a continuum of care graphically, showing how disease-modifying therapy with curative, life-prolonging, or palliative intent wanes as the illness progresses toward the end of a person's life, tapering to nonexistence as active dying begins in the last hours of life. Comfort-oriented symptom control and supportive care increase over time, maximizing as dying culminates in death. Often people receive this care through a hospice program. Anticipatory grief over many different losses begins before death. Bereavement continues for some time after death. Palliative care provides for all 3 phases for the family as well as for the patient.

Standards for hospice and palliative care

The hospice industry in the US is regulated by standards and guidelines promulgated by HCFA and measured and regulated by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). These standards may also be applied to palliative care.

Access

Hospice agencies cannot always provide care to all comers, but the obligation to care for the dying is such that turning patients away is intolerably difficult for many of them. The best hospices have tended to expand rather than limit access. Oregon is currently aiming for universal access to hospice care. Medicare benefits are not panoramic and should be well understood if you are to provide the best benefits available to patients who need them.

Informed choices

Delivery of care should meet the patient and family expectations as much as possible. Relevant expectations include having access to services, being informed and in control of treatments to relieve pain and other physical symptoms, and psychological, social, and spiritual support. Patients will be treated with the family as a unit of care, participate in choice of settings, choose among options for interventions including referrals for intervention, have adequate information sharing and confidentiality from other parties, and have absence of discrimination. Bereavement and grief support for survivors will continue even after the death.

Symptom management and support

Symptom management, mental and spiritual health, and social support often require different kinds of programs that were not anticipated when the Medicare hospice legislation was written in 1982. Many hospices have worked with their communities, hospitals, and physicians to develop programs that stand outside the Medicare-regulated hospice delivery model in order to meet the needs of patients and families. These have included palliative care units, bridge programs, and the like.

Grief and bereavement support

Support of the patient with anticipatory grief or grief over lost function, and support of the family for some time after bereavement are also important functions in end-of-life care.

Transfer options, continuity of care

Sometimes patients, with their families and physicians, decide that medical interventions that require hospitalization in an acute care facility are needed; transfer from home or a hospice facility is necessary. This is possible without jeopardizing the patient's place in hospice. As far as possible, continuity of providers between settings should be available.

Research and evaluation

Hospice care is a mature enough field that there is a responsibility for systematic evaluation, research, and education of incoming professionals in the same way that we are introduced to the rest of the spectrum of health care. Numerous committees, commissions, professional associations, and agencies are working with the nation's medical schools and graduate and postgraduate programs to be sure that physicians are well educated in their role in palliative care, as well as the way in which they can use hospice to promote best end-of-life care for their patients. Physicians are urged to support those developments, as well as the initiatives to critically study best practices so that the entire system may improve.

It is now up to us in the medical mainstream to make use of hospice as a routine part of medical care in the US. Hospice should no longer be viewed as an alternative to standard care; rather it represents an important resource in the completion of good medical care. This EPEC project is but one example of the widespread move to integrate the principles developed in hospice into mainstream medicine in order to provide its benefits to all dying patients. The challenge is to do this without losing the quality and safe personal touch of smaller systems of care. I urge each of you here to work within your own health care communities to be sure that the hospice agencies help you to take the best care of your patients and their families. If you are satisfied, let them know. If you are dissatisfied, work with them until it is right. If there is no hospice agency serving your area, then work with your community until there is one.

Summary

This plenary has attempted to place in a coherent picture a variety of conceptions of suffering, a framework of elements in end-of-life care, and a set of models and standards for the delivery of quality end-of-life care. Conceptions of suffering include fragmentation of personhood, stressed personal stories, opportunities for growth, and total pain. Elements of care can be divided into those that are fixed, which include the patient's racial, ethnic, cultural, and socioeconomic background, as well as the diagnosis and prognosis. Elements that can be modified include the symptoms suffered in the physical, mental, social, and spiritual realms. Interventions are not limited to professionals and health care delivery sites, but include those that can be mobilized by family, community, and others, and include social institutions or programs such as Medicare policy. Outcomes must be measured if systems are to be improved and measures are becoming available. Definitions and models of palliative and hospice care were provided, together with suggestions for setting standards for end-of-life programs.

Key take-home points

1. Patients' suffering has a context; patients and families must be considered together.
2. Palliative care defines a model for the relief of suffering and the improvement of quality of life across the spectrum of illness. What we now generally term palliative care has grown out of, and includes, hospice care.
3. Bodies do not suffer, only persons do. Personhood means having a past, present, and future. Suffering is a challenge to meaning. Loss of meaning is a form of suffering.
4. Elements in the broad conceptualization of end-of-life experience can be thought of in 4 categories: fixed elements, modifiable elements, interventions, and outcomes.
5. The biggest need in changing the system of care is timely application of knowledge that is already available.
6. Hospice should be a routine part of medical care in the US. It is not an alternative to standard care; rather, it represents an important resource in the completion of good medical care.
7. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relive suffering have been neglected in the training of physicians.

Resources

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EPEC

Education for **P**hysicians on **E**nd-of-life **C**are

Trainer's Guide

Procedure/Diagnosis Coding and Reimbursement Mechanisms for Physician Services in Palliative Care

Emanuel LL, von Gunten CF, Ferris FD. The Education for Physicians on End-of-life Care (EPEC) curriculum, 1999.

Special thanks to the EPEC Team, the EPEC Advisory Group, and all other contributors.

Objectives

The objectives of this section are to:

- understand how to code for physician services related to palliative care, including hospice
- understand the differences between the reimbursement mechanisms to be used when the patient is enrolled in the Medicare hospice benefit and the usual reimbursement mechanisms

Physicians can code and bill for services related to palliative care by using existing mechanisms. This section first discusses coding for physician services by standard coding approaches. Then it presents how those same approaches need to be adapted when a patient has elected the Medicare hospice benefit. Finally, it describes how palliative care services other than physician services are paid.

Coding for physician services related to palliative care

Coding for physician services, whether the patient is enrolled under the Medicare hospice benefit or receives health care services through other funding mechanisms, almost always uses the same coding technique. Physicians code for their service to an individual patient in two parts: 1) a procedure or service code and 2) a diagnosis code.

1) Procedure or service codes

The physician selects a procedure code from the Current Procedural Terminology (CPT)™ codes published by the American Medical Association. For physicians involved in palliative care, the most frequently used codes are the evaluation and management (E/M) codes (code range, 99201-99499). There are evaluation and management codes for each of the usual settings in which physicians provide services: ambulatory outpatient, acute inpatient hospital, extended care institutions, or patients' homes. Within each general category of codes (by setting) there is a hierarchy of codes from least intensive to most complex.

The Health Care Financing Administration (HCFA) has promoted extensive guidelines for the documentation that must support the use of each of the E/M codes. Related to palliative care, a little-known and underappreciated provision of current E/M coding guidelines often applies. When more than 50% of the patient-physician interaction is composed of counseling and/or information giving, then *time* becomes the factor that determines the level of service that is coded. As palliative care consultations and services often incorporate extensive amounts of information giving and/or counseling as part of the physician-patient interaction, then the time it takes to complete the activity determines which E/M code will be chosen. Each of the E/M codes is associated with a time element for this purpose. Table 1 indicates current codes with an amount of time associated with each.

When time is used to determine which E/M code to use, the documentation must indicate that more than 50% of the interaction was related to counseling or information giving. In the inpatient setting, the time is defined as floor or unit time, which includes the time that the physician is present on the patient's hospital unit and at the bedside rendering services for that patient. This includes time in which the physician establishes and/or reviews the patient's chart, interviews and examines the patient, writes notes, and communicates with other professionals and the patient's family.

Physicians who provide palliative care may also report codes for specific procedures or tests that they may perform (such as anesthetic injections, paracentesis, and thoracentesis). The time required to provide these procedures or tests is not included in the time used to establish the appropriate E/M code.

An example

You are asked to provide palliative care consultation for an 86-year-old former schoolteacher who has been admitted to the hospital for exacerbation of congestive heart failure. The attending physician would like advice on managing her dyspnea. You spend an hour on the unit reviewing the chart and interviewing/examining the patient and an additional 20 minutes writing your note and conferring with the attending physician. The majority (more than 50%) of your interaction with the patient was related to eliciting her values and care goals, clarifying her understanding of her diagnosis and prognosis, and giving information and counseling. You had some specific suggestions about the use of morphine to relieve her dyspnea.

You would code 99254 for this initial consultation in the hospital. In the note documenting the consultation, you would indicate the name of the referring physician, the reason for the consultation, the recommendations for medical management of the dyspnea, the fact that the majority of the interaction was related to counseling and information giving, and a summary of the situation and the information around which counseling or information giving was required. The note should indicate that the total time spent on the consultation, including the time spent in documentation and discussing the case with the referring physician, was 80 minutes.

2) Diagnosis codes

Besides the CPT code, the physician describes the reason for the service by using one of the International Classification of Disease—Clinical Modification (ICD-9-CM) codes promulgated by the National Center for Health Statistics (NCHS). These diagnosis codes are published by several publishers, including the American Medical Association. The ICD-9-CM book contains not only disease codes but also many symptom codes. A few examples are indicated in Table 2.

Many physicians, particularly internists, are concerned about reimbursement for concurrent care; that is, if they see a patient on the same day as another internal medicine specialist or subspecialist, only one of them will have their services reimbursed. In October 1995, HCFA published new rules that permit concurrent care by two or more physicians on the same day, even if they are of the same specialty. In order to describe the legitimate differences in evaluation and management services that multiple physicians may provide to a single patient, physicians need to use different ICD-9-CM codes for diagnosis as appropriate.

An example

For the 86-year-old woman with congestive heart failure described above, if both her general internist and the palliative care specialist use the ICD-9-CM code for congestive heart failure, only one submission for reimbursement is likely to be accepted and the other denied. However, if you are being consulted for advice related to management of shortness of breath, you would use the ICD-9-CM diagnosis code for dyspnea (286.6).

Reimbursement for physician services related to palliative care

Medicare hospice benefit background

The Medicare hospice benefit was established in 1982 to pay for hospice services at home for Medicare beneficiaries. Provision is also made for brief periods of inpatient services. A patient is eligible to elect the Medicare hospice benefit if the patient is confirmed by two physicians to have a prognosis of less than or equal to 6 months if the disease follows its usual course. The patient must acknowledge the terminal nature of the illness and sign election forms that indicate that care will be directed toward comfort, not cure of the disease. When a patient elects the Medicare hospice benefit, care for the patient that is related to the terminal illness is the direct responsibility of the hospice program. The benefit pays 100% for intermittent nursing, social work, chaplain, nurse aide, physical/occupational therapy, medication and therapy related to the terminal illness, and durable medical equipment. The hospice agency receives a per diem rate to cover these costs. This rate is set by the federal government and is not influenced by the particular treatments or services that the patient receives. As such, it is an example of capitated medical care. Many commercial payers have adopted similar approaches to covering home hospice care. If a patient needs medical care that is not related to the terminal illness, then that care can be provided and reimbursed by standard Medicare mechanisms. It is the responsibility of the hospice physician to determine whether care is related or unrelated to the terminal illness.

Payment and coding for physician services under the Medicare hospice benefit

1) Administrative/supervisory activities

As a part of the benefit, the services of the hospice medical director that relate to the administrative and general supervisory activities of the hospice are included in the *per diem*. "These activities include participating in the establishment, review, and updating of plans of care, supervising care and services and establishing governing policies" (Medicare Regulations, Section 406). Therefore, the medical director should expect his or her administrative services to be reimbursed from the hospice program in addition to fee-for-service billing for direct patient care.

2) Direct physician services to Medicare hospice patients

Physician services related to direct patient care under the Medicare hospice benefit are not covered as part of the *per diem* rate. Any physician who provides direct care, whether the hospice medical director or other physicians caring for the patient, needs to code for his or her services separately. The precise mechanism for reimbursement depends on whether or not the physician is associated with the hospice program either as an employee or as a volunteer.

3) Attending physician, not associated with the hospice

At the time the patient elects the Medicare hospice benefit, the patient indicates who his or her attending physician will be. The attending physician for the patient who is not associated with the hospice continues to code for physician services using CPT and ICD-9-CM in the way described above and submits bills for reimbursement to Medicare under Part B (the federal Medicare program that funds physician services from payments made by beneficiaries). However, for paper claims, the physician must indicate on the HCFA-1500 claim form that he or she is the attending physician and not an employee of the hospice program that is caring for the patient when each claim is submitted. If this statement is not present, the services are likely to be denied. For physicians who submit bills electronically (EMC), an HC modifier must be appended to the CPT code. The fiscal intermediary will then telephone the physician's office for further information. When the carrier calls, the information they need is, "This is a hospice patient; Dr. X is the attending physician and is not employed by the hospice."

4) Attending physician associated with the hospice

If the attending physician is associated with the hospice agency (eg, medical director or hospice physician), as a salaried employee or even as a nonsalaried volunteer, then codes for physician services are submitted to the hospice agency and submitted by the agency to Medicare under Part A (the federal Medicare program that covers institutional and nonphysician services funded by payroll deductions). This is a marked departure from other standard approaches to coding and billing for physician services. The hospice agency will submit these bills and are paid at 100% of the usual and customary fee reimbursed under Medicare Part B schedules. The hospice agency then can pass this reimbursement on to the physician as part of his or her negotiated salary or fee-for-service arrangement.

5) Consulting physicians

Consulting physicians who are asked to see the patient by the attending physician can also submit claims for the services they have provided to patients who have elected the Medicare hospice benefit. However, they must submit their code claims directly to the hospice agency, which in turn submits the claims for reimbursement under Part A. The consultants must have a contract with the hospice agency in order for this to occur.

Payment and coding for physician services outside the Medicare hospice benefit

1) Hospice under Medicaid/public aid

Hospice care is reimbursed by many states for their indigent patients. The Medicaid and public aid budgets are administered by individual states, not the federal government. However, most states have adopted HCFA/Medicare guidelines for patients who are receiving hospice care. Consequently, the coding guidelines outlined for the federal Medicare hospice benefit also apply. In state-managed programs, it is important that practitioners become familiar with the rules and regulations in the individual states in which they are practicing.

2) Private insurance

Most commercial payers (ie, health plans, insurance companies) require physicians to code for their services by means of CPT and ICD-9-CM codes. Physicians code and submit their claims for reimbursement regardless of whether a patient is covered by a hospice benefit. Again, specific regulations regarding coding may apply for an individual payer. Information on these rules should be obtained before claims are submitted.

3) Palliative care services for patients under Medicare

Physicians may see patients for purposes of delivering palliative care services when they are still covered under Medicare. Use the coding procedures outlined in the first part of this document and submit them to the Medicare fiscal intermediary in your area in the usual way.

Funding for nonphysicians providing palliative care services

Under the Medicare hospice benefit, the *per diem* fee covers all services of nonphysician health care professionals who provide care to the patient and family. However, patients who are not eligible or appropriate for enrollment under the Medicare hospice benefit may have legitimate needs for interdisciplinary palliative care services. The challenge is how to pay for the nonphysician component of such services. Many health care professionals, such as nurse practitioners, clinical nurse specialists, social workers, and chaplains, can access fee-for-service billing for patients not enrolled in the Medicare hospice benefit. In many settings, this has not been explored but is available. More commonly, these services are included as part of a larger program of services. For example, when a patient is hospitalized, the hospital reimbursement rate includes nursing, social work, and chaplaincy services.

Table I

Summary of some cpt evaluation/management codes

Attending/managing physician

New/ office	Established office	Initial hospital	Subsequent hospital
99201 10 min	99211 5 min	99221 30 min	99231 15 min
99202 20 min	99212 10 min	99222 50 min	99232 25 min
99203 30 min	99213 15 min	99223 70 min	99233 35 min
99204 45 min	99214 25 min		
99205 50 min	99215 40 min		

Nursing home-C	Nursing home-F	Home—new	Home—established
99301 30 min	99311 15 min	99341 20 min	99347 15 min
99302 40 min	99312 25 min	99342 30 min	99348 25 min
99303 50 min	99313 35 min	99343 45 min	99349 40 min
	99344 60 min	99350 60 min	
		99345 75 min	

Prolonged service face to face office/home	Prolonged service face to face inpatient
99354 30 min	99356 30 min
99355 each subsequent 30 min	99357 each subsequent 30 min

Consultation

A consultation is a type of service provided by a physician whose opinion or advice regarding evaluation and/or management of a specific problem is requested by another physician or other appropriate source. A physician consultant may initiate diagnostic and/or therapeutic services. The request and the need for consultation must be documented in the medical record. The opinion and any services ordered or performed must also be documented. A "consultation" initiated by a patient and/or family, and not requested by a physician, should be reported by means of the codes for confirmatory consultation or office visits, as appropriate. *The follow-up codes should not be used* if the consultant assumes responsibility for management of a portion, or all, of the patient's condition(s).

Office/home	Initial hospital	Follow-up hospital	Confirmatory
99241 15 min	99251 20 min	99261 10 min	99271
99242 30 min	99252 40 min	99262 20 min	99272 Low severity
99243 40 min	99253 55 min	99263 30 min	99273 Moderate severity
99244 60 min	99254 80 min		99274 Moderate to high
99245 80 min	99255 110 min		99275 Moderate to high

Table 2

Some common ICD-9 codes physicians may use in palliative care*

Anorexia	783.0	Inanition	263.9	Pain: unspecified	780.9
Agitation	307.9	Mental status change	780.9	Pain: abdomen	789.0
Anxiety	300.0	Nausea	787.02	Pain: arm	729.5
Confusion	298.9	Nausea & vomiting	787.01	Pain: back	724.5
Coma	780.01	Vomiting	787.03	Pain: bone	733.90
Cough	786.2	Weakness	780.7	Pain: chest	786.50
Debility	799.3	Weight loss	783.2	Pain: foot	729.50
Dementia	298.9	Shortness of breath	786.09	Pain: hip	719.45
Dyspnea	286.6	Unconscious	780.09	Pain: leg	719.45
Depression	311			Pain: Muscle	729.1
Delirium	780.09			Pain: sacroiliac	724.60
Diarrhea	558.9			Pain: throat	789.1
Fatigue	558.9			Pain: neck	723.1
Fever	780.6				
Headache	784.0				
Hemorrhage	459.0				

* Refer to the full tabular list of ICD-9-CM codes to ensure coding at the highest degree of accuracy.

End-of-life & palliative care websites

American Academy of Hospice and Palliative Medicine

http://www.aahpm.org

AAHPM is an organization for physicians who are committed to furthering and fostering the practice of hospice/palliative care for the terminally ill and their families.

American Academy of Pain Management

http://www.aapainmanage.org

This resource provides the names of credentialled pain practitioners and pain management programs by zip code; offers direct access to the National Pain Data Bank for outcome measurement; provides links to other pain-related sites; has information about the agenda for the annual clinical conference in September of each year.

American Academy of Pain Medicine

http://www.painmed.org/

The mission of the American Academy of Pain Medicine is to provide for quality care to patients suffering with pain, through the education and training of all physicians, through research, and through the advancement of the specialty of Pain Medicine.

ABCD- Americans for Better Care of the Dying

http://www.abcd-caring.com

ABCD is a non-profit coalition of citizens and professionals united to ensure that public policy addresses the needs of individuals and families coping with a fatal illness.

Agency for Health Care Policy and Research

http://www.ahcpr.gov/

AHCPR is the lead agency charged with supporting research designed to improve the quality of health care, reduce its cost, and broaden access to essential services.

The American College of Physicians-American Society of Internal Medicine (ACP-ASIM)

http://www.acponline.org/index.html

ACP-ASIM is a medical specialty society designed to enhance the quality and effectiveness of health care by fostering excellence and professionalism in the practice of medicine.

The American Geriatrics Society

http://www.americangeriatrics.org/

AGS is a professional organization of health care providers dedicated to improving and effecting change for the health and well being of all older adults.

American Pain Society

http://www.ampainsoc.org

APS is a non-profit multidisciplinary educational and scientific organization dedicated to serving people in pain, through research, education, treatment, and professional practice.

American Society for the Advancement of Palliative Care

http://www.asap-care.com

ASAP Care is a personal effort to help expedite the reform of terminal health care practice.

American Society for Bioethics and Humanities

http://www.asbh.org

ASBH is a professional society of individuals, organizations, and institutions interested in bioethics and humanities.

American Society of Law, Medicine and Ethics

http://www.aslme.org

ASLME provides high-quality scholarship, debate, and critical thought to the community of professionals at the intersection of law, health care, policy, and ethics.

American Medical Association

http://www.ama-assn.org:80/about.htm

The AMA is a membership organization of physicians. It serves as the patient's advocate, sets standards for the profession of medicine, medical education, policy matters, and much more.

Approaching Death: Improving Care at the End of Life

http://www2.nas.edu/hcs/21da.html

This report, from a committee of the Institute of Medicine, calls for changes to improve end-of-life care, better training of health care professionals, reform of outdated laws that inhibit the use of pain-relieving drugs, and testing of new payment options.

Association of Cancer Online Resources, Inc.

http://www.medinfo.org

The Association of Cancer Online Resources, Inc. (ACOR) is a non-profit patient advocacy organization founded to develop, support, and represent Internet based resources providing high quality, up-to-date information and support to cancer patients, and to provide open communication channels between and among patients, health professionals and research scientists.

Better Health

http://www.BetterHealth.com/

Better Health is an online interactive forum offering support and help on a variety of medical concerns and conditions

Cancer Net

http://cancernet.nci.nih.gov/

Cancer Net is a wide range of accurate, credible cancer information from the National Cancer Institute. The comprehensive cancer database includes summaries on cancer treatment, screening, prevention, and supportive care as well as information on ongoing clinical trials.

Caregiver Network

http://www.caregiver.on.ca:80/index.html

Based in Toronto, Canada the goal of CNI is to be a national single information source to make your life as a caregiver easier.

Caregiver Survival Resources

http://www.caregiver911.com/

Caregiving is becoming a significant issue for many people. This resource provides help to others to cope with the demands of caregiving.

Catholic Health Association of the United States

http://www.chausa.org

Catholic-sponsored health organizations provide the aged and chronically ill population with a broad spectrum of high-quality professional services.

Center for Disease Control and Prevention

http://www.cdc.gov/

The mission of CDC is to promote health and quality of life by preventing and controlling disease, injury, and disability.

Center for Medical Ethics and Mediation

http://www.wh.com/cmem

The Center for Medical Ethics and Mediation is an educational association dedicated to providing quality training, research, consultations and mediations for healthcare professionals and organizations.

Center to Improve Care of the Dying

http://www.gwu.edu/~cicd

CICD is an, interdisciplinary team of committed individuals, engaged in research, public advocacy, and education activities to improve the care of the dying and their families.

Choice in Dying

http://www.echonyc.com/~choice/

The nonprofit organization provides advance directives, counsels patients and families, trains professionals, advocates for improved laws, and offers a range of publications and services.

Chronicle of Philanthropy

http://www.philanthropy.com/

The newspaper of the non-profit world.

Clinical Care Options-HealthCare Communications Group

http://www.healthcg.com/

A state of the art medical resource for healthcare professionals.

The Commonwealth Fund

http://www.cmwf.org/index.html

The Commonwealth Fund engages in independent research on health and social policy issues.

Death, Dying and Grief Resources

http://www.katsden.com/webster/index.html

This web site represents a large and comprehensive collection of Internet resources with a holistic perspective of the death process.

Death NET

http://www.rights.org/~deathnet/open.html

DeathNET is an international archive specializing in all aspects of death and dying with a sincere respect for every point of view, encompassing the legal, medical, and cultural aspects of human mortality.

Department of Health and Human Services, Healthfinder

http://www.healthfinder.gov

healthfinder™ is a consumer health and human services information web site, which can lead you to, selected online publications, web sites, and not-for-profit organizations..

Dying Well

http://www.dyingwell.com/

Defining Wellness through the 'End of Life': Resources for patients and families facing life-limiting illness.

Eldercare Web

http://www.elderweb.com/index.shtml

Eldercare Web, is a collection of reviewed links to on-line information about health, financing, housing, and other issues related to the care of the frail elderly.

Elizabeth Kubler Ross, M.D., “On Death and Dying”

http://www.doubleclickd.com/kubler.html

Elizabeth Kubler-Ross, M.D. is widely recognized as one of the foremost authorities in the field of death & dying. “On Death and Dying”, is required reading in most major medical and nursing schools and graduate schools of psychiatry and theology.

EPEC Project

http://www.ama-assn.org/ethic/epec

The Education for Physicians on End-of-life Care (EPEC) Project, supported by a grant from the Robert Wood Johnson Foundation, is an ambitious two-year initiative designed to educate physicians across the United States on the essential clinical competencies in end-of-life care that every physician should have.

Extended Care Information Network

http://www.ElderConnect.com/

The Extended Care system matches patient needs with providers or agencies that can accommodate them and produces a professional package of information to be presented to the patient and their family with information about any providers/agencies they might want to look into.

FACCT -- The Foundation for Accountability

http://www.facct.org/

FACCT works to ensure that Americans have clear, accurate information about quality that they can use to make better health care decisions.

The Foundation Center

http://fdncenter.org/index.html

The Center collects, organizes, analyzes, and disseminates information on foundations, corporate giving, and related subjects.

Grantmakers in Health

http://www.gih.org/

The mission of GIH is to increase the capacity of private-sector grantmakers to enhance the health and well being of all people.

Growthhouse

http://www.growthhouse.org/

This web site is an international gateway to resources for life-threatening illness and end-of-life issues.

Hemlock Society USA and PRO-USA

http://www.hemlock.org/hemlock/index.html

For those who support the rights of the terminally ill to choose death with dignity, who support personal control and autonomy in end-of-life decisions, and who believe that laws should allow a terminally ill person the choice of medical assistance in hastening their death

Idealist

http://www.idealist.org/usfound.htm

With 14, 000 organizations under one roof, this site will allow you to look for organizations, volunteer and job opportunities and much more.

International Association for the Study of Pain

http://www.pslgroup.com/dg/1ff02.htm

IASP is open to scientists, physicians, dentists, psychologists, nurses, physical therapists, and other health professionals actively engaged in pain research and to those who have an interest in the treatment of pain.

Last Acts

http://www.lastacts.org

Last Acts is a call-to-action campaign dedicated to improving end-of-life care through the sharing of ideas and solutions by professional care givers, institutions and individuals.

Lindesmith Center

http://www.lindesmith.org/about_tlc/pain.html

In response to inquiries from state legislatures, medical examiners, regulators, and doctors regarding the appropriate use of opioids by physicians, the boards of directors of APS and AAPM have promulgated a consensus statement, "Use of Opioids for the Treatment of Chronic Pain."

Medical College of Wisconsin Palliative Care Program

http://www.mcw.edu/pallmed/

This program is committed to improving care for the dying in America through the development, implementation and dissemination of innovative education and clinical care programs.

Medicare Rights Center

http://www.medicarerights.org

The Medicare Rights Center (MRC) provides free counseling services to Medicare beneficiaries who cannot afford private assistance for Medicare-related issues.

Memorial Sloan Kettering Cancer Center

http://www.mskcc.org

Memorial Sloan-Kettering Cancer Center's web site provides a wide range of information for medical professionals, patients, their families, and the general public.

National Association for Home Care (NAHC)

http://www.nahc.org/

NAHC is committed to serving the home care and hospice industry, which provides services to the sick, the disabled, and the terminally ill in the comfort of their homes.

National Conference of State Legislatures

http://ncsl.org/programs/pubs/endoflife.htm

The NCSL report helps state lawmakers make informed decisions regarding assisted suicide; pain management and other end-of-life care policies.

The National Institute on Aging

http://www.nih.gov/nia/

NIA promotes healthy aging by conducting and supporting biomedical, social, and behavioral research and public education.

The National Center for Health Statistics

http://www.cdc.gov/nchswww/about/about.htm

NCHS provides statistical information that will guide actions and policies to improve the health of the American people.

National Family Caregivers Association

http://www.nfcacares.org/

NFCA is predicated on the belief that caregivers that choose to take charge of their lives, and see caregiving as but one of its facets, are in a position to be happier and healthier individuals.

National Hospice Organization

http://www.nho.org/

Founded in 1978, the National Hospice Organization is the oldest and largest nonprofit public benefit organization devoted exclusively to hospice care. NHO is dedicated to promoting and maintaining quality care for terminally ill persons and their families, and to making hospice an integral part of the U.S. health care system.

The Nathan Cummings Foundation

http://www.ncf.org/ncf/aboutncf/about.html

The Nathan Cummings Foundation seeks to build a society that values nature and protects ecological balance for future generations; promotes humane health care; and fosters arts to enrich communities.

New York State Partnership for Long-Term Care

http://www.nyspltc.org/about/index.html#3

*This Partnership is an innovative program that combines private long-term care insurance and Medicaid to help New Yorkers prepare financially for the possibility of needing nursing home or home care***.**

Not Dead Yet

http://acils.com/NotDeadYet/

Americans with Disabilities want freedom and life.

OncoLink

http://www.oncolink.com

The University of Pennsylvania Cancer Center provides easy access to a wide variety of cancer resources including current clinical trials, financial issues for patients and more.

Oregon Health Sciences University Center for Ethics in Health Care

http://www.ohsu.edu/ethics/

The Center for Ethics combines the perspectives of health professionals, patients, and families to improve teaching, research and clinical consultation about ethical issues in patient care and health policy.

Oversight Hearing: "Assisted Suicide in the United States" -- April 29, 1996

http://www.house.gov/judiciary/2.htm

This site will keep you informed about Judiciary Committee activities and other important issues facing our nation.

Pediatric Pain

http://is.dal.ca/~pedpain/prohp.html

This site provides professional, research, and self-help resources for health care workers, researchers, and parents caring for children in pain.

Project on Death in America

http://www.soros.org/death/

The mission of the Project on Death in America is to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts, and to foster innovations in the provision of care, public education, professional education, and public policy.

Resource Directory for Older People

http://www.aoa.dhhs.gov/aoa/dir/intro.html

This Resource serves older people and their families, health and legal professionals, social service providers, and others with an interest in the field of aging.

The Robert Wood Johnson Foundation

http://www.RWJF.ORG/main.html

RWJ is the nation's largest philanthropy devoted exclusively to health and health care, and has made more than $2 billion in grants.

SeniorScape

http://www.seniorscape.com/

SeniorScape is a source for information on elder law, community resources for elders, senior health and nutrition, lobbying efforts, geriatric care, financial management in later years and much more.

UB Center for Clinical Ethics and Humanities in Health Care

http://wings.buffalo.edu/faculty/research/bioethics/index.html

The Center for Clinical Ethics and Humanities in Health Care is an interdisciplinary academic center which draws upon a wide range of individuals from the School of Medicine and Biomedical Sciences as well as various health care and academic institutions.

UW Pain and Policy Studies Group

http://www.medsch.wisc.edu/painpolicy

The UW Pain and Policy Studies Group is the study of public policy in relation to pain management, identifying and addressing the barriers to medical use of opioid analgesics.

The Video Health Information Project

http://www.sebridge.org/~vhip/

VHIP provides free access to consumer health information in a large collection of videotapes.

"When Death is Sought Assisted Suicide and Euthanasia in the Medical Context"

http://www.health.state.ny.us/nysdoh/provider/death.htm

The New York State Task Force on Life and the Law published a 217 page report titled "When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context," and has been made available electronically

Originally compiled by the Project on Death in America. Modified by the EPEC Project, 7/99.

WHAT ARE THE MAJOR DIFFERENCES BETWEEN THE LIVING WILL AND THE DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

DURABLE POWER OF ATTORNEY FOR HEALTH CARE	LIVING WILL
• Appoints someone to make health care decisions for you and permits you to specify guidelines and limitations, if you wish • Encompasses all health care decisions, including requesting or refusing treatment or care • Applies to any kind of illness or injury that incapacitates you • You need someone you trust who is willing to take on this responsibility • Can be flexible to changing circumstances • Is easily revoked, orally or in writing • Need not specifically address nutrition, hydration, or any other condition	• Applies only to terminal conditions that leave you unable to make or communicate decisions • Spells out in writing under what circumstances you want medical care withheld or withdrawn • Need not use suggested form • Refers only to withholding or withdrawing care • Does not put decision-making responsibility on a specific person • Is static and may not cover every possible medical situation • Is easily revoked, orally or in writing • Must specifically address nutrition, hydration, and resuscitation

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FAQ DURABLE POWER OF ATTORNEY FOR HEALTH CARE

1) ***What is Durable Power of Attorney for Health Care?***

- It is a legal document through which you may have your wishes for medical care carried out. It is only used when you are unable to make or communicate decisions regarding medical treatment. It is prepared before any condition or circumstance causes you to be unable to actively participate in medical decisions. It will allow you to specify desires and to appoint an agent to act in your interests.

2) ***Why would I want to create a Durable Power of Attorney for Health Care?***

- Durable Power of Attorney for Health Care protects your wishes for medical treatment in the event that you are incapable of expressing them. It allows you to appoint a trusted agent to carry out your interests and allows you to specify to that agent and to your physician information declaring your desires for certain treatments. While discussing issues of end-of-life can be difficult, creating a document that will express your wishes will lessen the burden on family and friends if a time comes when they must make medical decisions in your place.

3) ***How will my wishes be considered if I do not have an advance directive?***

- In this case your physician will consult with others to try to determine what your wishes were. If you have discussed your wishes with your physician he or she will know them and will act in your interests. If they are unaware they will discuss what your wishes are with next of kin or close relatives about withdrawing or withholding life support systems. You are advised to complete some form of advance directive rather than relying on oral instructions if you want to be sure that your wishes will be understood and known in the event that you are unable to state them yourself.

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4) What is a health care agent?

- A health care agent is a person whom you authorize through an advance directive to convey your wishes concerning treatment. A health care agent does not act in any other medical decisions and does not act if you are able to communicate your own wishes.

5) Who should I appoint as my health care agent?

- The only people who can NOT serve as your agent are
  - Your treating health care provider: physician, nurse, hospital, nursing home
  - A non relative employee of your treating health care provider
  - An operator of a community care facility
  - A non relative employee of an operator of a community care facility

  You can appoint a relative, a close friend, coworker, religious council or any other person who you trust to make health care decisions in your best interest.

6) Do I need a lawyer to create Durable Power of Attorney for Health Care?

- No. You do not need a lawyer to create a Durable Power of Attorney for Health Care. You can use the forms provided in the Rhode Island Durable Power of Attorney for Health Care. The only thing you need to complete the forms is two witnesses who are not 1) a person who is designated as your 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 **OR** one notary public who also meets the aforementioned requirements.

7) What type of information may be specified in my durable power of attorney?

- Durable Power of Attorney for Health Care allows you to specify whether they want or do not want life-sustaining treatment, nutrition, intubation, respirator, procedures, CPR, hydration, antibiotics, and pain management. None of these things are denied by creating a Durable Power of Attorney for Health Care, but a specification can be made about any of them and a patients agent will have the power to see to that wish being carried out.

8) Is there any time in which my Durable Power of Attorney would not be recognized?

- Durable Power of Attorney for Health Care is not recognized by emergency services, rescue, or ambulance personnel. The one exception to this is transferring residents from nursing homes who have do not resuscitate orders.

9) Is the Rhode Island Durable Power of Attorney accepted in other states?

- The state of Rhode Island recognizes other states Durable Power of Attorney for Health Care. Because of reciprocity laws, other states should also recognize the legality of a designated agent under Rhode Island law. If you were to move to another state, or plan to spend extensive time in another state, it would be advisable to check that states laws to guarantee recognition of the Durable Power of Attorney for Health Care.

10) How long does the Durable Power of Attorney for Health Care last? Does it need to be renewed?

- Durable Power of Attorney for Health Care need not be renewed or updated. Its validity stands unless another authorization pre-empts it. Basically, unless the decision is made to change or complete a new Durable Power of Attorney for Health Care, the wishes expressed in your most recent document will be those carried out. It is advisable to reassess the document every few years in order to guarantee that agent information is up to date, and that your desires for treatment and who should represent your interests have not changed. If you wish to enact a time limit on the Durable Power of Attorney for Health Care, one can be specified in the forms provided. Unless specified, the Durable Power of Attorney for Health Care is in effect until revoked.

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11) Who should I provide copies of my Durable Power of Attorney for Health Care to in order to ensure that my wishes are properly carried out?

- Although you are not required to provide copies of the Durable Power of Attorney for Health Care to anyone, it is most effective if it is accessible to those people who will be making health care decisions. Therefore, copies should be provided to the health care agent who is designated in the document, any alternative agents who have been identified, family, physicians, and hospital. By having your desires for treatment and decision making made apparent to this group of people, they can work more appropriately to carry out your wishes.

12) How would I go about changing my agent?

- Because relationships change over time, it is important to examine the decisions that you have made about your health care agent. If you decide that the person who you have appointed would no longer properly represent your wishes, then you can revoke the power of your agent by notifying that person, your physicians or the hospital either verbally or in writing. If you choose to appoint a new agent, the Durable Power of Attorney for Health Care form can be redone appointing a new person to be your agent. If you do not appoint a new agent, then the originally appointed alternative agent will become your primary agent.

13) If my agent dies, does the first alternative that I appointed automatically become my agent, or must I redo the forms?

- Yes. If you would like to appoint someone other than your first alternative, then it would be necessary to redo the Durable Power of Attorney for Health Care form.

14) Where can I get a copy of the form to create RI Durable Power of Attorney for Health Care?

- The form to create a Durable Power of Attorney for Health Care can be obtained from the Attorney General’s web page at ***www.riag.state.ri.us***. Hard copies will also be made available in other public places such as hospitals, community care clinics, elderly service programs, etc.

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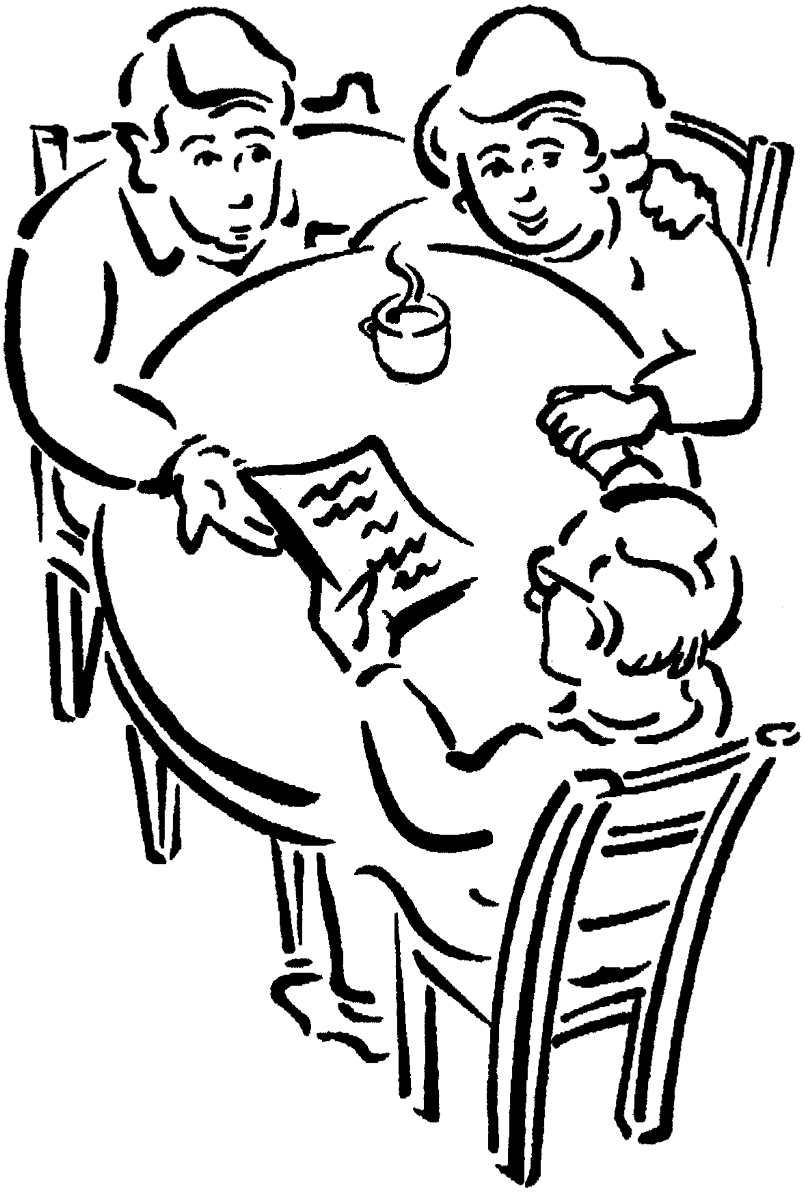
Your Life
Your Choices

Planning for Future Medical Decisions:

How to Prepare a Personalized Living Will



Your Life
Your Choices

Planning for Future Medical Decisions:

How to Prepare a Personalized Living Will

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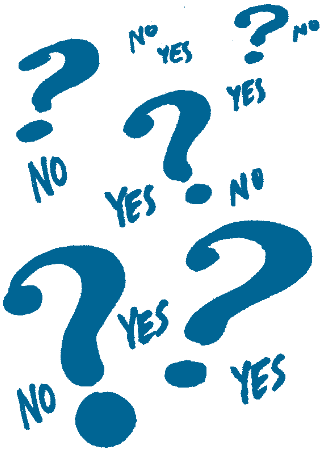


"What should we do for Dad?"

"We got the kind of call we'd feared. Dad had been in declining health for months. Then he fell asleep at the wheel and was in a bad car accident. Three weeks later he was still in a coma. A breathing machine pumped air into his lungs because he could not breathe on his own. The doctors thought his chances of coming out of the coma were slim. They talked with Mom and me about turning off the breathing machine and allowing Dad to die naturally. I felt terrible. I didn't think Dad would want to be kept alive like this. But I knew Mom would feel guilty for the rest of her life if we told the doctors to "pull the plug" while there was still even the slightest hope. We weren't sure what we should do because Dad never told us what he would have wanted. I really wish we'd talked about this before."

Your Life, Your Choices

There's only one person who is truly qualified to tell health care providers how you feel about different kinds of health care issues—and that's you. But, what if you get sick, or injured so severely that you can't communicate with your doctors or family members? Have you thought about what kinds of medical care you would want? Do your loved ones and health care providers know your wishes?

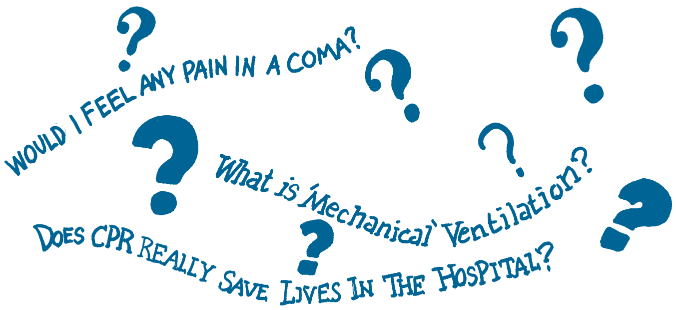
Many people assume that close family members automatically know what they want. But studies have shown that spouses guess wrong over half the time about what kinds of treatment their husbands or wives would want.

You can help assure that <u>your</u> wishes will direct future health care decisions through the process of *advance care planning.*

What do you need to do to guide your future health care?

1. Figure out what you want.

Think. You need to understand what kinds of situations you might face and the options for care.



2. Communicate this to others.

Talk. Tell your loved ones and health care providers about your strongly-held beliefs and what kinds of care you would want in different situations.

Forms are included in the back of this workbook. It can take as little as 15 minutes to fill them out.

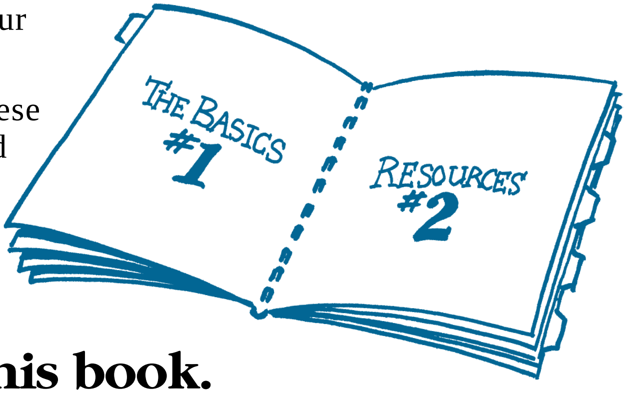
Write. Write down your wishes so your loved ones will have a record of what you told them. This also helps if no one is around who can speak for you.

How to use this workbook.

This workbook has two parts.

Part I: The Basics. This 14-page section introduces and discusses all of the important components of advance care planning. You may find it provides enough information for you to figure out what you want and express your wishes to others.

Part II: Resources. Turn to these sections for additional help and further explanation of ideas and topics introduced in "The Basics."

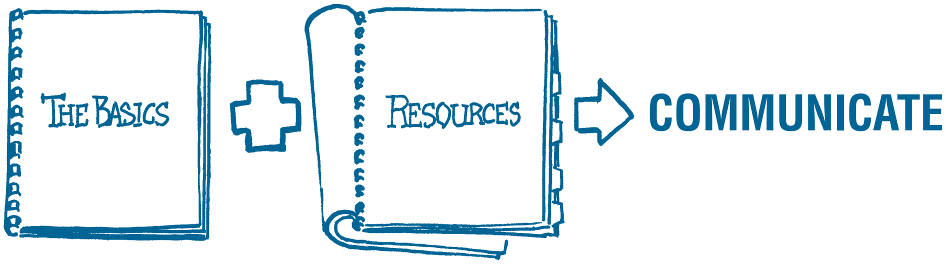


Two ways to use this book.

Spend an hour working through "The Basics." Then communicate.

OR

Work through "The Basics." Take another hour or two to work through all or part of "Resources" for a more complete approach. Then communicate.



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Why do you need to think *now* about future health care decisions?

Whether you are young or old, healthy or sick, there may come a time when an important decision needs to be made about your health care. And whether it's tomorrow or five years from now, there's no guarantee that you will be able to express your wishes for yourself at that time. Consider the Larsen family:

> **Chris Larsen never told his family** what kind of medical measures he'd want if he became critically ill. He is in a nursing home after having suffered a severe stroke 9 months ago. He is paralyzed and unable to take care of himself or communicate in any way. Now he has pneumonia and will probably die unless he goes to the hospital to receive intravenous antibiotics. He also may need to be on a breathing machine for a week or so. The doctor says that his chances of returning to normal are remote, but that he has a fair chance of getting over the pneumonia. His family members disagree about what they should do. His son Bill says, "Dad was never a quitter. He'd want to fight to the very end, as long as there was the slightest hope." His daughter Trudy disagrees. "Sure, Dad wasn't a quitter, but he wanted to die naturally—he would be horrified to be kept alive this way."

In fact, Trudy's views were the closest to Mr. Larsen's true opinion. But the family never had a way to find this out. They treated his pneumonia and he lived another year in the nursing home without recovering his ability to communicate or care for himself.

This story shows why it is so important to discuss your wishes. Talking with your family and health care providers ahead of time can prevent confusion and help ease the burden on them.

Do you have any strongly-held beliefs that should guide your care?

Think ahead. Imagine being in a critical condition—one in which you were unable to communicate your wishes. If medical decisions could mean the difference between life and death, what would you want your loved ones and health care providers to do?

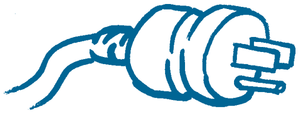
Your strongly-held beliefs can guide these choices because they help others understand what you value about life. But be sure to explain your beliefs because people often use the same words to mean very different things. Consider the cases of Mrs. Santini and Mrs. Johnson, both deeply religious women.

> **"I want to be kept alive as long as possible,"**
>
> Maria Santini has said on many occasions. "Life is sacred and has meaning, no matter what its quality."

> **"When my time comes, keep me comfortable."**
>
> Irene Johnson also believes life is sacred. However, she has often said, "I've lived a long and full life. I don't want anything done just to keep me alive."

Because Mrs. Santini and Mrs. Johnson both believe that life is sacred, many people would assume that their views on being kept alive would been the same. But, as you've seen, it's not that simple.

Here's another example. Have you ever heard anyone say, "If I'm a vegetable, pull the plug"? What does this mean to you? What's a vegetable? What's a plug? Even people who live together can have very different ideas about what the same words mean without knowing it. The story of May and John Williams shows how important it is to be specific about what you mean.



When you say, "pull the plug" it could mean a variety of things:

- Stop the breathing machine
- Remove the feeding tube
- Don't give me antibiotics
- Stop everything

"I'd never want to live like a vegetable." Both May & John Williams have always shared this belief during their fifty years of marriage. But when they were talking about their advance care plans, they learned that they had very different views about what that meant. For May, it's when she can't take care of herself. John was surprised. For him, being a "vegetable" is much worse. "It's when my brain's not working but my body is being kept alive by machines."

People have very different notions of what it means to be a "vegetable." Here are some more examples:

- "You sit in a chair and don't do anything all day."
- "You can't read anymore."
- "You're just a body with some life in it."

If you couldn't speak for yourself, what would you want done for you?

Think about the following statements. Do you agree with any of them? Discussing your answers with others can help them understand what is important to you and where you stand with respect to health care decisions.

My life should be prolonged as long as it can, no matter what its quality, and using any means possible.

Pages 21-26 have exercises to help you specify your beliefs and values in more detail.

I believe there are some situations in which I would <u>not</u> want treatments to keep me alive.

I'd want my religious advisors to be consulted about all medical decisions made on my behalf to make sure they are in keeping with my religious teachings.

My personal wishes would not be as important as what my family thinks is best for me.

I'd want to have my pain controlled, even if the medications make me sleepy or make it difficult to have conversations with my family.

Who will speak for me if I can't speak for myself?

For people with close family members, choosing a spokesperson may seem simple. If you are married, your health care providers will ask your spouse to speak for you. If you are not married, other relatives usually are consulted. However, if these people disagree, it can be very difficult for health care providers to know whom to listen to.

Sometimes your closest next-of-kin is NOT the person you would like to speak for you. In that case, you can formally appoint the person of your choice to be your "voice." You can give this person the legal authority to make health care decisions for you using a "durable power of attorney for health care." The following story shows why this is so important.

Larry Roberts assumed his doctor would listen to his closest friend, Mrs. Alice Jergen, for advice about his wishes for medical treatment. She'd been visiting him daily since he entered the final stages of lung cancer and they talked about it often. Three days ago, he developed an infection and became delirious with a high fever. Before making a decision about whether to start him on antibiotics, Mr. Roberts' doctor felt it was appropriate to consult his next-of-kin. This turned out to be his brother Frank, who lives in another state. Frank and Mrs. Jergen disagreed about what medical treatment Mr. Roberts should have. Mr. Roberts never talked about this with his brother. But because Mrs. Jergen was not related to Mr. Roberts and had no legal authority, the doctor followed his brother's advice.

A durable power of attorney for health care ensures that the right person will speak for you when you can't speak for yourself.

Common questions about choosing a spokesperson.

Q: *What happens if I don't appoint a spokesperson?*

A: Health care providers will consult with someone close to you. They will usually contact your next-of-kin, starting with your spouse. If you are married and want your spouse to be your proxy, then doing nothing is probably OK. If you are separated from your spouse but not divorced, health care providers will still ask your spouse to make decisions for you.

If you are married, your spouse will be recognized as the person to make decisions on your behalf, unless you have a durable power of attorney for health care that appoints someone else.

Q: *Can a friend be my spokesperson?*

A: Yes, but unless you appoint your friend as your spokesperson, using a durable power of attorney for health care, he or she may not be consulted or may be overruled by family members.

Q: *What happens if some family members don't agree with my spokesperson about what's best for me?*

A: Health care providers usually will give treatment while they try to reach agreement about what to do. The best way to prevent disagreements is to communicate with everyone ahead of time to let them know who you've picked and what you want.

Q: *Who is the best person to be my spokesperson?*

A: Think about the people in your life and ask yourself the questions below.

- Who knows me well?
- Who would do a good job representing me?
- Who is available to come to my side if needed?

Q: *What if I don't know anyone who I want to be my spokesperson?*

A: Your best choice is to write down your wishes and give a copy to your health care provider. Fill out a legal form, such as a living will, with as much detail as possible. Include a personalized statement, such as the exercises from this book, to provide a better understanding of your wishes.

See page 20 if you need more help deciding who is the best person to be your spokesperson.

Q: *Do I need to talk to my spokesperson now?*

A: Yes, because you need to make sure they are willing, and to tell them about your wishes so they'll know what to do for you.

What else can I do to make my wishes known?

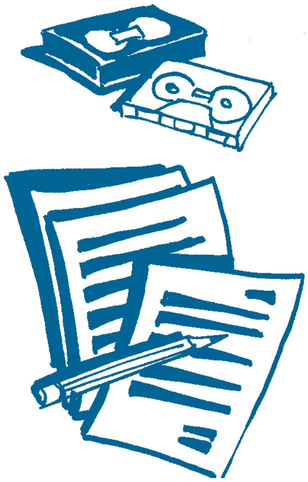
It is good idea to write down your wishes for future health care because it gives others the most complete picture of how you feel and what you would want. You can do this by signing an **advance directive**, which can be either a formal, legal document or an informal statement of your wishes. There are two types of formal directives: proxy and instructional.

There are 3 steps to advance care planning:

1. Think through your preferences
2. Talk about your wishes with others
3. Document your wishes

Completing an advance directive or writing a personalized statement are ways to accomplish the third step.

A ***proxy directive*** uses a legal document called a "durable power of attorney for health care" to appoint a spokesperson who can make health care decisions on your behalf. It goes into effect when health care decisions need to be made for you <u>and</u> you can't communicate or make health care decisions for yourself.



Instructional directives, such as a "living will" or "directive to physicians," are written instructions to physicians in the event you cannot speak for yourself. They usually tell health care providers which treatments you would not want if you become *terminally ill* or end up in a *permanent coma*.

You can personalize your advance directive with exercises from this workbook, a letter, or even a tape.

A ***personalized statement*** lets you express what is most important to you. In addition to talking with loved ones and health care providers, you can make this statement by including the exercises from this workbook, writing a letter to your loved ones, or making an audio or video tape.

Which directive is best?

It depends on your situation. You could complete either a proxy or instructional directive, both, or just a personal statement. Most health care providers like proxy directives best because it means they will have someone to talk with who knows you well. But not everyone has a proxy to represent them. In that case, an instructional directive will help your health care providers decide what's best for you. Either way, adding a personalized statement helps others feel more confident that they are doing what you would have wanted them to do.

Common questions about advance directives.

Q: *Why should I complete an advance directive?*

A: Advance directives are legal documents that help you keep control over future health care decisions. They can also relieve your loved ones of the burden of making life and death decisions on your behalf.

Q: *When do advance directives go into effect?*

A: Only if you become unable to understand your medical treatment options or are unable to communicate your wishes for medical treatment.

Q: *What's the difference between a "living will" and a regular will?*

A: A living will, like all advance directives, is restricted to decisions about your health care. It goes into effect while you are still alive but unable to communicate. A regular will pertains to your estate and property. It goes into effect after your death.

Blank copies of advance directive forms are located in the back pocket of this workbook.

Q: *What should I do with my advance directive after I've signed it?*

A: You should give a copy to each person whom you want to be informed of your wishes, including your health care providers. Keep a list of their names. Put the original in a place where others can easily find it. Do *not* put your only copy in a safe-deposit box because it may not be easy to get if someone needs it. You can also fill out the wallet card (in the back) to let people know where they can find a copy.

Q: *What if I change my mind about what I want after I've completed an advance directive?*

A: You can always change your directive. Either write the changes on your existing directive (initial and date the changes), or destroy the old one and write a new one. Be sure to give revised copies to everyone who has a copy of your older version.

Q: *I have homes in 2 states. Is my advance directive valid in both places?*

A: States often have different laws and different forms. It may be best to complete separate forms for each state. Check with your health care providers in each place.

What situations and decisions do people commonly face?

There are many situations in which people are not able to talk or communicate their wishes because of illness or injury. The following stories describe the kinds of decisions family members, friends and health care providers must make when people can't speak for themselves. As you read these stories, try to think about how you would value the quality of your life in each situation and whether you would make the same kinds of decisions for yourself.

Dementia

Lily Chen, an elderly widow, was diagnosed 4 years ago with Alzheimer's disease, a common form of **dementia**. Over time she has gradually been losing her ability to think clearly and make decisions. Now she doesn't remember where she is and she can no longer recognize her daughter who visits her every day. For the last 8 months, she has been completely dependent on nurse's aides to bathe and feed her. Recently, she stopped eating altogether. Her daughter has power of attorney for health care and has to decide whether to have a **long-term feeding tube** surgically placed into her mother's stomach. The surgery is quick and won't cause much pain, but the real issue is guessing how Mrs. Chen would value her current life. If they place the feeding tube, Mrs. Chen could live for many more years in the same or worse condition. If they don't, she will die in about 2 weeks or less, and probably won't feel hungry or thirsty .

*Go to "More information about health conditions and treatments" for greater detail. See page 29 for **dementia**, page 34 for **feeding tube**, page 28 for **coma (and PVS)**, and page 35 for **ventilator**.*

- *The percent of people with dementia increases with age. At age 65, it's about 5%, at age 75, it's 10-20%, and at age 85, it's about 35%.*
- *With Alzheimer's disease the mind fails before the body—many people are otherwise healthy.*
- *In the advanced stages of dementia, people typically do not know where they are or recognize family members. They frequently stop eating, even with help from others.*

Questions to consider:

Do you think Mrs. Chen's daughter should decide about the feeding tube based on the fact that her mother isn't eating, or based on her mother's memory problems and dependence on others for care? Why?

Coma

Tom Rice was 29 years old when he was hit by a car as he was riding his bicycle. He was taken to the hospital where he went into a **coma**. He lay in bed with his eyes closed—it looked as if he were asleep, except that he didn't respond when people talked to him and he didn't wake up. He was put on a **ventilator**, or breathing machine, that pumped air into his lungs because he couldn't breathe on his own. He also had a **feeding tube** down his throat so liquid food and fluids could go straight into his stomach.

Tom was single so his parents were asked to decide whether to continue the treatments that were keeping him alive. His doctors thought Tom might come out of it but that it could take anywhere from one week up to a year. They said that the longer Tom remained in a coma, the less likely it was that he would ever wake up. They thought that if he did come out of the coma, he would probably have severe brain damage. He would need help taking care of himself and would not be able to live alone.

Tom had never said anything about what he would want if he were in an accident. His parents kept him "hooked up" for weeks and weeks to give him every chance. After 2 months, they decided it was hopeless since he hadn't changed in all that time. They stopped all treatment and Tom died that same day.

- *People in a coma don't feel pain or any other sensations.*
- *Comas can be caused by injury, illness, drug overdoses and heart stoppage. Predicting the outcome of coma depends on what caused it, how long the person has been in coma, and age.*
- *Doctors say that it can take 3-4 weeks to see whether a person will come out of coma or go into a related condition, "persistent vegetative state" or **PVS**.*

Questions to consider:

Do you think Tom's parents kept him alive long enough? Too long? Why do you feel this way?

What if Tom were 69 instead of 29? Would it make a difference? Why?

Stroke

Flora Park woke up one day and couldn't move her left arm. Her vision was blurred and she was having difficulty talking. Her husband called her doctor who told her to go to the hospital—he suspected a **stroke**. After a long day of tests, the doctors agreed it was a stroke. They started her on medication and rehabilitation therapy. After a few more days, her sight improved and she was talking clearly again. After two months, she could move her arm but it was still a little clumsy and weak. Her therapist taught her ways to make the most of her weak arm. She was adjusting to her new situation, but she worried constantly about what would happen if she had a more serious stroke.

She talked about this with her husband and their children. She said, "This stroke has made me think long and hard about what's important to me. The doctor said that even with my medications, I could have another stroke and I might not be able to tell you what I want. So I'm telling you now. I love life and don't want to give up. That's why I'd be willing to go to the hospital and start rehab again to see whether I can get better. But if I get to a point where I'll never be able to feed myself or do anything on my own, then I don't want anything done to prolong my life. That means no **CPR** if my heart stops and no machines. My biggest fear is that I won't be able to talk with you or enjoy your company. I'd rather die quickly than suffer a long, slow decline."

Questions to consider:

Do you share Mrs. Park's views about when she wouldn't want treatment to prolong her life?

For you, is there such a thing as unacceptable quality of life? Where would you draw the line?

- *Risk factors for stroke include being over age 55, high blood pressure, heart disease, diabetes, smoking, high cholesterol and family history.*
- *Stroke is the #1 cause of adult disability. Impairments can be mild, moderate or severe, depending on what part of the brain is affected.*
- *Most recovery of lost sensations or function occurs within the first 3-6 months after a stroke.*
- *People who've had a stroke have a 5-10% chance of having another one. The first few months after their first stroke is the time when they are at greatest risk.*

*See page 30 for more on **stroke**, page 33 for **CPR**, page 31 for **terminal illness** and page 36 for **hospice**.*

Terminal illness

Carlos Ruiz had severe heart disease for years. His doctor said, "Your heart is much worse and it will continue to get weaker. Now we need to make some decisions about your goals for care. One approach would be to concentrate on supporting your heart, lung and other vital organs to extend your life as long as possible. Another option would be to make relief of pain and discomfort our highest priority, even if it meant you might not live as long. Which of these approaches sounds right for you?"

Mr. Ruiz said, "I've lived with this bad heart for a long time. I'm tired of fighting, but I'm not quite ready to give up. I'd try simple treatments, especially if I can be at home with my family. I'd rather be comfortable than live a long time."

Mr. Ruiz' doctor gave him a referral to a **hospice** nurse who started visiting him at home. He got a few lung infections which made it hard to breathe. He cured them by taking antibiotic pills at home. Then he got another infection that didn't get better, despite taking antibiotic pills. He had a high fever and was so sick that his wife had to decide what to do. His doctor and hospice nurse said they could put him in the hospital to treat his infection which would relieve his symptoms and might prolong his life. Or he could stay at home with additional comfort measures until he died.

Mrs. Ruiz sent him to the hospital because she thought he might get better and could return home for a little while longer.

Questions to consider:

Do you agree with Mrs. Ruiz's decision to send her husband to the hospital? Do you think she followed his wishes?

- *With **terminal illness**, the underlying disease can no longer be cured. Most people with a terminal illness are expected to die within 6 months.*
- ***Comfort care** includes medications for pain and other symptoms, and keeping the person clean and dry. Sometimes treatments such as blood transfusions, antibiotics, or chemotheraphy are used to provide comfort by relieving symptoms.*
- *People who are close to death often go "in and out" of awareness, being alert only part of the time.*

Telling others what you want.

Your loved ones and health care providers need to know how you feel if they are to carry out your wishes in the future.

Raising this topic is not always easy. If your family members and friends are uncomfortable talking or even thinking about these issues, consider these ideas to get a discussion started:

For more ideas about ways to start a conversation about your wishes or what to talk about, turn to page 45.

- Begin on a positive note by talking about how much you value them and their willingness to listen to you.
- Share one of the stories from this workbook to show how planning in advance can ease the burden on family members.
- Remind them that accidents can happen to anyone at any time and that you just want to be prepared.

Including others in a discussion about what you want can also help clarify your wishes in your own mind. Consider the story of Mr. Nakamura:

Kenji Nakamura wanted to appoint his daughter Suzy to be his spokesperson. The first time he tried to talk to her about this she said, “Dad, you’re going to live to be 100 years old! We don’t need to talk about this now.” The next time she came over he eased into the conversation by talking about the things he was thankful for, including his health. Then he asked her to look at the statement of his wishes that he’d been writing. Suzy was surprised to learn that her dad never wanted to be kept alive by machines. She said, “What if you only needed a breathing machine for a few days?” After talking about it they both had a clearer understanding of his wishes — he didn’t want to be kept alive on a ventilator *forever*, but a short time would be OK.

Writing it down.

Even if you've talked about your wishes, when the time comes, stress and strong emotions can cause your loved ones to forget what you told them or wonder if they are making the right decision. A written document can help keep things straight.

You may document your preferences formally using advance directives. If you want to fill out either a proxy and/or instructional directive, the forms are in the back of this workbook.

Some people are more comfortable documenting their wishes informally in a letter or an audio or video tape. It seems more personal. You can also personalize formal advance directives by attaching these informal statements or any of the exercises from this workbook.

Either way, "writing it down" means you've left a record of your wishes that everyone—family, friends, and health care providers—can use as a general guide or as explicit instructions. You won't have to worry that your wishes will be forgotten or misunderstood.

Blank advance directive forms are located in the back pocket. The exercises throughout this workbook can be used to personalize these forms.

"What you say is in the air, what you write is always there."

Suzy was glad her dad had written his wishes down when Mr. Nakamura fell and broke his hip. While he was in the hospital, he got pneumonia and became confused. His doctors asked Suzy whether they should put him on a ventilator if he had trouble breathing. She shared his advance directive with the doctors and explained her father's fears of being kept alive forever by a machine. As a result, they decided to start antibiotic treatment, and if needed, they would put Mr. Nakamura on a breathing machine for only a short period of time. If he didn't seem to be improving, they would stop the breathing machine and focus their attention on keeping him comfortable. Suzy was thankful that her father had insisted on discussing his wishes.

What's Next?

Talk about it...

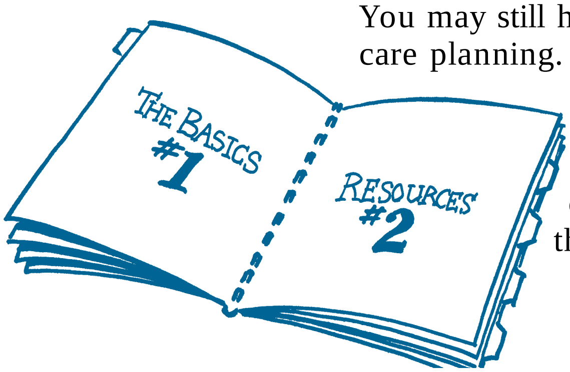
Now that you've read through "The Basics" of advance care planning, you may feel ready to talk about your wishes with your family and health care providers. If you need help starting the conversation, see pages 46 to 50 for some ideas.

Write about it...

Sometimes it helps to have a few thoughts on paper. Try pulling out the forms in the back of the book and filling them out. Don't worry about making them perfect—there are two sets of forms so you can always go back and finalize your thoughts. The important thing is to get started.

Learn more...

You may still have some questions about advance care planning. The "Resources" sections that follow are designed to give you a better understanding of specific topics. You can refer to only the sections that concern you, or read it straight through—whichever works for you.



Here's a sample of the kinds of questions that are answered in the Resources section:

	For more details:
• What makes life worth living?	➡ *see page 21*
• What's likely to happen if you have a serious stroke? What do you need to think about in advance?	➡ *see page 30*
• What if someone you love needs a feeding tube? What are the pros and cons?	➡ *see page 34*
• What can you do to keep the courts out of these advance care planning decisions?	➡ *see page 51*

Thought-provoking exercises.

Which exercises should I complete?

You can complete any or all of them. Each of the exercises addresses different issues, including:

1. What to consider when choosing a spokesperson (page 20),
2. Your wishes regarding what makes life worth living (page 21),
3. Your personal and spiritual beliefs that affect medical decision making, and your feelings about hope and risk taking (pages 22-23),
4. Your wishes regarding the way you might spend your last weeks or days if you were dying, and other related matters (pages 24-26).

We recommend that you complete at least the exercises on pages 21-24. These will be the most useful to others if they have to make decisions for you.

You may want to ask your religious advisor to help you think through the questions about quality of life, medical interventions, and death and dying. Religions have different philosophies about what to do under the situations described in these exercises.

I don't like writing in books. Besides, I'm not ready to write down my answers. What should I do?

We have included a copy of these exercises in the back of the workbook. You can use these to draft your ideas.

What should I do with these exercises once I've completed them?

- Use them to discuss your values with your loved ones and health care providers.
- Attach them to your advance directive as your personal statement. They will provide greater details about your wishes.
- Put your initials and date on each page so others will know when you filled them out.
- Review them each year — your answers could change with time.

Initials & Date: ____________

Who should speak for me?

Instructions This exercise will help you choose the best spokesperson for you. On the top of each column, write in the names of one or more people you're considering to be your spokesperson. Place a check mark (✔) in the column for that person if the following statements are true. The first two statements must be true for your spokesperson to have legal authority to represent you. You should weigh how important the other attributes are to you in deciding your first choice.

	Names		
Meets the legal criteria in my state for durable power of attorney for health care (see the instructions in the back pocket).			
Would be willing to speak on my behalf.			
Would be able to act on my wishes and separate her/his own feelings from mine.			
Lives close by or could travel to be at my side if needed.			
Knows me well and understands what's important to me.			
Could handle the responsibility.			
Will talk with me now about sensitive issues and will listen to my wishes.			
Will be available in the future if needed.			
Would be able to handle conflicting opinions between family members, friends, and/or medical personnel.			
Other issues important to me: ________________________ ________________________ ________________________			

Initials & Date: ______________

What makes your life worth living?

Instructions This exercise will help you think about and express what really matters to you. For each row, check (✔) one answer to express how you would feel if this factor by itself described you.

Life like this would be:

	difficult, but acceptable	worth living, but just barely	not worth living	can't answer now
a. I can no longer walk but get around in a wheelchair.				
b. I can no longer get outside—I spend all day at home.				
c. I can no longer contribute to my family's well being.				
d. I am in severe pain most of the time.				
e. I have severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath).				
f. I rely on a feeding tube to keep me alive.				
g. I rely on a kidney dialysis machine to keep me alive.				
h. I rely on a breathing machine to keep me alive.				
i. I need someone to help take care of me all of time.				
j. I can no longer control my bladder.				
k. I can no longer control my bowels.				
l. I live in a nursing home.				
m. I can no longer think clearly-I am confused all the time.				
n. I can no longer recognize family/friends				
o. I can no longer talk and be understood by others.				
p. My situation causes severe emotional burden for my family (such as feeling worried or stressed all the time).				
q. I am a severe financial burden on my family.				
r. I cannot seem to “shake the blues.”				
s. Other (write in):				

Instructions To help others make sense out of your answers, think about the following questions and be sure to explain your answers to your loved ones and health care providers.

If you checked "worth living, but just barely" for more than one factor, would a combination of these factors make your life "not worth living?" If so, which factors?

If you checked "not worth living," does this mean that you would rather die than be kept alive?

If you checked "can't answer now," what information or people do you need to help you decide?

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Instructions Circle yes, not sure, or no to indicate whether you agree with each statement. If you do not agree with the "always" statements, this could mean that you agree with these statements some of the time, but not always. You can use the space at the bottom of the page to explain and clarify your beliefs.

Personal and spiritual beliefs

Many people have special personal or spiritual beliefs that they want respected in decision making about life-sustaining treatments. What are yours?

I believe that it is always wrong to withhold (not start) treatments that could keep me alive.	**Yes**	**Not sure**	**No**
I believe that it is always wrong to withdraw (stop) treatments that could keep me alive after they've been started.	**Yes**	**Not sure**	**No**
I believe it is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a permanent coma.	**Yes**	**Not sure**	**No**
I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells.	**Yes**	**Not sure**	**No**
I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf.	**Yes**	**Not sure**	**No**

(write in name) ________________________________

I believe in other forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care:	**Yes**	**Not sure**	**No**

____

I believe that controlling pain is very important, even if the pain medications might hasten my death.	**Yes**	**Not sure**	**No**
I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf.	**Yes**	**Not sure**	**No**
I believe that it is acceptable to consider the financial burden of treatment on my loved ones when making health care decisions on my behalf.	**Yes**	**Not sure**	**No**
I believe that my loved ones should follow my directions as closely as possible.	**Yes**	**Not sure**	**No**

Additional beliefs and/or explanations for my beliefs:

____

____

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Hope for recovery

People have different feelings about hope that influence what health care they want. What are your feelings about hope?

Imagine that you are very sick and have been told that you will very likely die soon.

I would want all possible treatments, even though my doctors don't think they will help me, because I would hope for a miracle cure that would prolong my life.	**Yes**	**Not sure**	**No**

Imagine that you have been in a coma for three weeks. The doctors think that the chance that you will ever return to your previous state of health is very small.

I would want to be kept alive indefinitely because I would still hope for a new medical development that would help me to recover.	**Yes**	**Not sure**	**No**

Weighing pros and cons of treatment for different chances of recovery

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. A big question is, how much would you be willing to endure if the chance of regaining your current health was high? What if the chance was low? Answer the questions below to carefully evaluate your own willingness to take such risks.

Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments have very severe side effects, such as severe pain, nausea, vomiting, or weakness that could last for 2-3 months.

I would be willing to endure severe side effects if the chance that I would regain my current health was:

high (over 80%)	**Yes**	**Not sure**	**No**
moderate (50%)	**Yes**	**Not sure**	**No**
low (20%)	**Yes**	**Not sure**	**No**
very low (less than 2%)	**Yes**	**Not sure**	**No**

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How would you like to spend your last days?

Many people have strong opinions about what would be important to them at the very end of their lives. For some, they want to express things they would like to have happen. Others want to be sure that certain things they dislike or fear will be avoided. What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

Instructions For each row, check (✔) one answer to express how important these issues would be to you if you were dying.

	Not Important	Moderately Important	Very Important	Extremely Important
a. Avoiding pain and suffering, even if it means that I might not live as long.				
b. Being alert, even if it means I might be in pain.				
c. Being around my family and close friends.				
d. Being able to feel someone touching me.				
e. Having religious or spiritual advisors at my side when I die.				
f. Being able to tell my life story and leave good memories for others.				
g. Reconciling differences and saying “good-bye” to my family and friends.				
h. Being at home when I die.				
i. Being in a hospital when I die.				
j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious.				

k. What are your biggest hopes about the end of your life?

____

____

l. What are your biggest fears about the end of your life?

____

____

Initials & Date: ____________

Other related matters

The topics that have been covered up to this point have related to decisions about your health care in the event you could not speak for yourself. Your decisions about the next topics would go into effect after your death. We include them here because they are related issues that you may want to communicate to others. There is a list of organizations and other resources on page 52 if you need more information about these related matters.

Organ donation and autopsy

Sometimes after death, organs and tissues can be used to help other people who need them. Family members must give consent to transplant your organs. You can help them make this decision by letting them know how you feel about this. After an autopsy, the body can be shown and buried.

Instructions Circle one word to express how you feel.

I want to donate any viable organs/tissues.	**Yes**	**Not sure**	**No**
If yes, have you filled out an organ donor card?			
Have you told your family?			
I consent to the use of all or part of my body for medical research.	**Yes**	**Not sure**	**No**
If yes, do you have a preference for a research institution?			
Have you told your family?			
I permit an autopsy.	**Yes**	**Not sure**	**No**

Burial arrangements

People often leave instructions about what they want done with their bodies after they die. Some want to be buried in a particular place, perhaps in a cemetery with other family. Other people would prefer to be cremated and have their ashes put or scattered in a special place. You can indicate your preferences by answering the questions below.

I would prefer to be: (circle one) **Buried** **Cremated** **No preference**

I would like my remains to be placed: ______________________________

Other preferences: ______________________________

____

____

Initials & Date: ____________

Funeral or memorial services

People have different ideas about funerals and memorial services. These services are often very comforting to family and friends as they celebrate and honor the life of their loved one. Services also can make a statement about one's religious faith. Write in below any thoughts about a funeral or memorial service such as where it should be held, songs or readings to be included, where donations should be sent, information for an obituary notice, or other wishes.

More information about health conditions and treatments

What will I learn from this section?

This section is intended to be a reference that will answer your questions such as,

- What's it like to be in a coma?
- What would happen if you needed CPR?
- Is being on a mechanical ventilator (breathing machine) like being in an iron lung?
- What are the key things to think about when making decisions about life-sustaining treatments?

Where can I get answers to other questions?

If you still have questions after you've read these pages, you can:

- Ask your doctor. Take these pages with you to your next appointment so your doctor can give you more specific information about what these health conditions and treatments might mean for you, given your current health condition.
- Call one of the organizations listed on page 52.

Coma

What is it?

Coma is a state of unconsciousness that persists for some time. It may be caused by a head injury, a severe stroke, bleeding in the head, or a severe illness. A person who is unconscious shows little or no movement or response to stimulation. It usually looks as though they were asleep. A related and more serious condition is called persistent vegetative state (PVS). A person in PVS is unconscious but sometimes opens his or her eyes and may have unintentional movements such as yawning, and random movements of the head or limbs. PVS usually develops after about a month in a coma.

What's it like?

People who have been in a coma (and then come out of it) usually say they have no memory of any awareness at all during the coma. These people generally report no memory of pain or discomfort. Those few people who say they were aware of things going on around them or hearing what was being said near them were not in a true coma. Observation of coma patients typically shows no sign that the patient is in any pain or distress. People in coma do not get out of bed, or communicate in any way. They are usually cared for in a hospital or nursing home because they need to have all of their personal care done for them including being fed through a tube, having their body wastes cleaned up, and being turned every few hours to prevent bed sores.

What's likely to happen?

Just after a person goes into a coma, it is very hard to predict what will happen. If and when the person comes out of a coma depends on his or her age, what caused it, and his or her overall health. People have very little chance of ever coming out of coma that was caused by illness after about 3 months, or one that was caused by a head injury after about 12 months. There are stages of coma. A person in a lighter stage of coma has a better chance of coming out of it than someone in deeper stages.

What are the key things to think about?

Would you want to be kept alive after the point in time when your doctors think that you probably won't ever come out of the coma?

Would you want to be kept alive if the doctors felt sure that if you were to come out of the coma, you would have permanent brain damage or other severe limitations?

Dementia

What is it?

Dementia is a condition in which there is a loss of memory and other mental functions, serious enough to affect interacting with other people. The most common types of dementia are due to Alzheimer's disease, AIDS, and multiple strokes. Other types of dementia can occur as a result of head injury, heavy use of alcohol, or thyroid problems. With the most common forms of dementia, mental functions get worse over time. These include memory, thinking, talking, problem solving, and perception.

What's it like?

Some people in the early stage of Alzheimer's disease may be aware of their forgetfulness, but as the dementia progresses, they will become totally unaware of the forgetfulness and other mental deficits. They will lose the ability to concentrate. Later, there may be mood changes whereby they may lose interest in things around them, or become agitated or violent on occasion even with family members. In still later stages, they becomes less active, less talkative. In the latest stages, they may no longer recognize close family or friends, lose their sense of day and night, and wander around the house at odd hours.

What's likely to happen?

Most types of dementia are irreversible and will get worse over time. Exceptions include dementia caused by thyroid problems, as well as memory problems due to depression which are treatable and may be reversible. The speed of deterioration is unpredictable, but severe dementia from Alzheimer's usually occurs within 5-10 years from the first signs of memory loss. In later stages, people with dementia become incontinent, losing control of their bowels and bladder. They often require nursing home care because they need daily help with feeding, dressing, and bathing and this is often more than most families can handle. As they lose interest in eating, complications of malnutrition such as infections and skin ulcers can lead to death.

What are the key things to think about?

If you had severe dementia and then became ill with a reversible illness, such as pneumonia, would you want treatment even though the treatment would not help your memory problems? What if treatment included going to the hospital?

If you were unable to eat enough and were severely demented would you want to receive your nutrition and fluids through a feeding tube placed directly into your stomach?

Some people with dementia seem happy while others seem sad or upset. If you were severely demented, how much should other people pay attention to your mood when making decisions about what it best for you?

Stroke

What is it?

Someone who has sustained an injury to a part of the brain, either because of a blockage in the blood vessels, or a burst blood vessel, is said to have had a stroke. Strokes rank third among all causes of death and are a major cause of long-term disability, but not all strokes cause disability. The kind of disability a person develops depends on what part of the brain is damaged and how severely. A stroke is also known as a “cerebrovascular accident,” or a CVA.

What’s it like?

The most common effects of a stroke are: (1) weakness or loss of movement and sensation in an arm, a leg, or both on one side of the body, (2) difficulty speaking, (3) partial loss of sight in one or both eyes,(4) trouble swallowing, and (5) problems understanding what other people are saying. Some people experience changes in their mood or personality. Depression is common among people who have had a stroke, often because of injury to the brain.

What’s likely to happen?

With the most minor of strokes, a person has a loss of feeling or ability to move a part of the body for less than a few days. With moderate strokes, a person may lose the ability to use one arm, need to walk with the assistance of a cane or walker, and have some slurring of speech. With serious strokes, a person might lose the use of one entire side of the body, need assistance to get out of bed and into a chair, or may not be able to speak or understand others at all. With the most severe strokes, a person often loses consciousness and falls into a coma. Most recovery from strokes happens within the first few days up to about 3 months, though modest improvements may continue up to 12 months. After that, whatever disability remains is likely to be permanent.

What are the key things to think about?

Every stroke is different and so is a person's ability to adapt to losses in function and disability. Many people find that with time and help they can adjust to their new circumstances after a stroke. If you had a stroke, what level of disability do you think you would want to live with? Are there some situations that you would find unacceptable? If so, what are they?

Terminal illness

What is it?

Every illness that causes death has a terminal stage. That stage is defined as the point when treatments can no longer work to reverse the illness or keep the disease from getting worse. No matter what treatments are given, the person is going to die within a short time. It is very hard to predict exactly how much time a person has to live at this stage, but most doctors expect they will live about six months or less.

What's it like?

During a terminal illness people often lose strength and become confined to bed either in their own home, or if they need more help, in a hospital, nursing home, or hospice (see page 36). Their bodies will begin to shut down. This may or may not be accompanied by pain. Some terminal illnesses, such as the later stages of cancer, can be painful, although medications can control the pain. Appetite usually diminishes. As people get closer to death they will almost certainly think and communicate less clearly.

What's likely to happen?

Near death there are times when people are not able to express their wishes clearly. Some people experience short periods of mental confusion, for example, they drift in and out of awareness over the course of a day. Many people lapse into a coma just before they die. For example, they may become dehydrated or develop an infection that, if it is not treated, could cause death more quickly than their primary terminal illness. If the treatments for these conditions are successful, they would postpone the moment of death and might prolong any suffering or discomfort associated with the terminal illness.

What are the key things to think about?

If you had a terminal illness, what would be the most important thing for you: relieving suffering or prolonging life?

What would be your goals for treatment of any other problems if you had a terminal illness? Treatment for secondary problems (such as an infection) would not cure the primary terminal illness (such as cancer or heart disease).

Kidney Dialysis

What's the problem?

If your kidneys stop functioning, waste products build up in your bloodstream. As a result, you may feel sick to your stomach, tired, weak, have little appetite and have swelling. In addition, you may have difficulty breathing or thinking clearly.

What's kidney dialysis?

Dialysis is a process in which your blood is circulated outside your body into a machine that removes waste products. A needle is inserted into one of your veins (usually in your arm) and an attached tube carries a steady flow of your blood into the machine. After the blood is cleaned, it is returned to your body through a second tube and needle that is inserted into another part of your vein. You lie in a bed next to the machine during each dialysis session, which usually lasts about four hours. You probably have three sessions a week. If you need long-term dialysis, you have an operation to place a shunt (special blood vessels) in your arm so the needles can be inserted repeatedly over time without collapsing your veins.

What happens if I decide not to get dialysis?

If the waste products in your bloodstream continue to accumulate, you will feel worse and worse. After some time you will go into a coma and then (usually within a week), your heart will stop. How quickly this occurs depends on your overall condition, but can be between a few days to a month. If you go through this process, you would receive care to keep you as comfortable as possible.

What are the good points of getting dialysis?

Dialysis allows people with kidney disease the chance to lead a near-normal life. Dialysis can relieve some of the symptoms associated with kidney failure. For those patients who are eligible for a kidney transplant, dialysis can keep them alive while they wait for a donor.

What are the bad points of getting dialysis?

Dialysis takes over one of the many functions of your kidneys, so it can't do as good a job as a healthy kidney. Because of this, waste products build up in your body between dialysis sessions, which means that at times, you may not feel very well. You will have to be careful about the amount and types of food you eat. You also will be more prone to infections, bleeding from your stomach or bowel, swelling or bloating, and be easily fatigued.

You will have to spend at least 12 hours a week on a dialysis machine. You may have to travel to a dialysis center for care, which will involve additional time and possibly help from others.

If you have another serious illness besides kidney failure, especially those involving your lungs, liver, or heart, dialysis treatment may be hard to take because of difficulties regulating your body fluids and waste products.

CPR— Cardiopulmonary Resuscitation

What's the problem?

During a life-threatening illness or a heart attack, your heart may suddenly stop beating and you may stop breathing. Or your heart may beat so irregularly that it no longer effectively pumps blood to your brain. These events mostly occur for people with heart disease, but can also occur without any known cause. Soon after blood stops moving to your brain you will lose consciousness and not be aware of anything going on around you.

What's CPR?

CPR involves vigorous pressing on your chest to keep blood circulating while electrical shock is applied to your chest to "jump start" your heart. Mouth-to-mouth breathing is used to restart your own breathing, or a breathing tube is placed into your windpipe and air is pumped into your lungs to help you breathe. You receive medications through a tube placed in one of your veins. Typically, all this goes on for about 15-30 minutes.

What happens if I decide not to get CPR?

With or without CPR, you will almost immediately lose consciousness. Without CPR, death will follow in about five to ten minutes.

What are the good points of getting CPR?

If you are in relatively good health when you need CPR, it can return you to roughly the same state you were in when your heart stopped. For people with some types of heart disease, CPR can restore an irregular heart beat. Pain or discomfort is not an issue while you receive CPR because you are not conscious during the process.

What are the bad points of getting CPR?

After CPR, however, you could have a sore chest or broken ribs because of the electrical shocks and vigorous massage. In addition, the chest compressions could result in a collapsed lung, which would require additional treatment. Most people who need CPR need a mechanical ventilator to support their breathing afterwards.

The success rate for CPR depends on many things: your overall health when you need it, where you get it (in the community or in the hospital), your age, and how quickly it starts after your heart stops beating. If you are under age 65, the success rate ranges between 25-40%. If you are over age 65, this rate drops to between 1-4%. CPR is rarely successful if you already have a chronic illness that affects your vital organs, such as your heart, lungs, liver, or kidneys. Less than ten out of 100 hospitalized patients respond to CPR by returning to the state they were in before their heart stopped. Of those who survive, many continue to live, but in a weaker state or with significant brain damage because blood could not get to their brain in time. CPR could keep you from dying, but you might live in a coma or be unable to think clearly.

Feeding Tubes - Artificial delivery of nutrition and fluids

What's the problem?

You may find yourself unable to swallow food. This could happen after an accident that damages your throat. It could also happen if you are unconscious or have some kinds of brain damage. When this happens you will be unable to take in enough food and water by mouth to keep yourself alive.

What's a feeding tube?

A feeding tube is used to carry liquid nutrition and fluids into your body. One kind of tube goes up your nose, down your throat, and into the stomach. This is called a nasogastric tube. It is about 1/8 of an inch in diameter. Another kind of tube is surgically placed into the wall of your stomach. The operation is quick and safe and you will feel little discomfort. Once the tube is in place it is painless.

What happens if I decide not to get a feeding tube?

If you don't receive any nutrition or fluids you will fall into a state much like a deep sleep. This will take about one to three weeks, during which time, you will be kept comfortable. For example, ice chips on your lips will help keep them moist. Usually, after several days, you will no longer experience thirst or hunger. Also, you will not feel pain as easily as you do now. Within a day or two after you enter this deep sleep, your heart will fail and death will follow within five to ten minutes.

What are the good points of getting a feeding tube?

A feeding tube can provide your nutritional and fluid needs. With adequate nutrition, you will be less likely to get bedsores. A feeding tube is not painful, although the kind that goes down your nose (nasogastric tube) can be uncomfortable. The surgically placed stomach tube is easy to manage without help from others as long as you can take care of yourself. With this kind of tube, you can pour the liquid nutrition into the tube, move about and bathe, all on your own. This tube is placed under your clothes, so other people would not know you have one.

What are the bad points of getting a feeding tube?

Having a tube down your throat will feel somewhat uncomfortable and unpleasant, although not truly painful. You could aspirate liquid (get it into your lungs) which can cause pneumonia. With either tube, you will not be able to taste anything. Receiving fluids might make it harder for you to control urination if you are confined to a bed.

If you are already in the terminal stage of an illness, a feeding tube will likely postpone your death. Tube feeding also makes it possible (in some cases) to keep people alive who are in a coma, have severe strokes, or severe dementia for a long time, even if they might not have wanted it.

Mechanical Ventilators (Breathing machines)

What's the problem?

You may not be able to breathe on your own for a number of reasons. Perhaps you have been in an accident that has damaged your airways. You might have a serious lung disease, or maybe you have suffered brain damage. You need a machine to breathe for you, either for the short term (a few hours to a few days) or for the long term (the rest of your life). It may be impossible to tell how long you will need it.

What's a mechanical ventilator?

Mechanical ventilators (also called breathing machines or respirators) completely take over the task of breathing. A tube is placed into your windpipe, either through your mouth or nose or through a small surgical incision at the base of your neck. The tube is about 3/4 of an inch in diameter, about as big as a dime. The tube will make it hard or impossible to talk. Most patients on a mechanical ventilator are in a hospital, usually in an intensive care unit. They are usually not able to get out of bed. In some situations, a portable ventilator allows a patient who is completely paralyzed to get around in a specially-equipped wheelchair.

What happens if I decide not to get a mechanical ventilator?

Without some external breathing assistance, you will die quickly. If you stop breathing, you will die within five minutes. You could be given medications that will sedate you. These medications help you relax so you will not panic or feel like you are struggling for breath.

What are the good points of getting a mechanical ventilator?

Mechanical ventilation is a painless, although often uncomfortable, way to continue your life. It is often needed for only a short time, for example, just long enough to let your body recover from a serious illness. In some cases, it can relieve the discomfort of feeling breathless. If you need a ventilator for a long time, it can sustain your life indefinitely when you might otherwise die.

What are the bad points of getting a mechanical ventilator?

Even if you are conscious, you will not be able to talk very well or at all. You will likely be confined to bed. You will also be dependent on others to bathe, feed, and dress you and to take care of your bowels and bladder. Nurses will also need to suction your lungs to keep them clear of mucous. It may be hard to tell how long you will need to be on a ventilator. If you have a terminal illness, a mechanical ventilator will only prolong dying.

Hospice and Palliative (Comfort) Care

What's hospice care?

Hospice is an approach to caring for people with terminal illness. The goal of hospice is to provide comfort care to control pain and other physical symptoms, and deal with the emotional and spiritual needs of dying persons and their families in the last 6 months of life.

Hospice care usually involves a team of professionals, including a nurse, a social worker, a doctor (although not always your personal doctor) and a chaplain or other spiritual advisor. Other health care providers and volunteers, such as physical therapists and chore workers, are called in as needed.

Hospice care can be provided in the home or in special care units in hospitals and nursing homes. The home hospice team usually comes to the house 1-3 times a week, but is available by phone 24 hours a day.

What are palliative care and comfort care?

The terms palliative care and comfort care are both used to mean relieving symptoms and minimizing discomfort. Examples include medications and other treatments to control pain, nausea, fatigue and shortness of breath. They also include nursing care to keep you clean, dry, and comfortable.

Sometimes, curative treatments, such as antibiotics, blood transfusions, chemotherapy, or even surgery, are offered to patients as palliative care because these treatments can make them more comfortable.

Palliative and comfort care should be given to all people experiencing discomfort. They are <u>not</u> just for people who are in the last months of life or who are getting hospice care.

What happens if I decide not to get hospice care?

Your health care providers will continue to treat new symptoms or infections as they occur. They will treat you either in or out of a hospital, depending on how much care you need. They tend to focus on relieving discomfort due to physical symptoms. They often do not focus on addressing the emotional and spiritual needs of dying people.

What are the good points of getting hospice care?

Hospice care is a holistic approach that focuses on helping dying people make the most out of each day.

Many people seek hospice care so they can die at home. Hospice can support the patient and family to make this happen.

What are the bad points of getting hospice care?

Agreeing to hospice usually means that patients must recognize and accept that their illness cannot be cured and that they will probably die in the next 6 months. Some people view this as a failure because they think it means they are giving up.

Usually, getting hospice care at home means that patients must have family or friends who can provide hands-on care up to 24 hours a day. Therefore, sometimes it's easier for patients, as well as their loved ones, to get their final care in a hospital.

Your specific health care preferences

Why should I fill these out?

- These forms are very specific about your wishes. You can attach them to your advance directive to provide a detailed picture of your preferences.
- In conditions when you can't speak for yourself, health care providers want to know how you feel about different treatments, especially CPR, mechanical ventilators, and feeding tubes. These forms will make it easier for your family and health care providers to give you the care you want.

Why are there 3 parts to each page?

The 3 parts reinforce each other. Treatment decisions are often based on thoughts about quality of life. For example, if people think that life with severe dementia would be difficult but acceptable, they might want some treatments but not others that would keep them alive.

- Part A lets you express your feelings about the quality of life for each of the different health conditions. This is helpful for your loved ones and caregivers.
- Part B gives a clear message about each treatment. This is very useful to health care providers.
- Part C gives you room to explain your reasons for Parts A & B, such as why you would want some treatments but not others.

Why does comfort care have a checkmark (✔)?

Because no matter what else you decide, your health care providers will alway try to give you medications and care to keep you clean and comfortable.

Initials & Date: ____________

Current Health

The information on this page could help others make decisions for you if you become unable to speak for yourself. The first part will give others an overall sense of how you view your current health situation.

Part A: Feelings about quality of life

Check the answer that best describes how you feel about your current health.

My life right now is just fine	My life right now is difficult, but acceptable	My life right now is worth living, but just barely	My life right now is <u>not</u> worth living
☐	☐	☐	☐

Part B: Preferences for different life-sustaining treatments

Imagine that you develop a life-threatening illness and couldn't speak for yourself. The doctors feel there is a good chance you would recover to your current health, but you might need one or more of the following treatments.

Check an answer for each treatment that best reflects what you would want.

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✔		
Other treatments: (fill in)			

Part C: Reasons for my decisions or other comments

Initials & Date: ____________

Permanent Coma

Imagine you are in a permanent coma (see pg. 28 for details). This means you:

- do not think, hear, or see anything
- are not in any pain
- are confined to a bed because you cannot move
- need 24-hour nursing care for bowel and bladder functions and skin care

Part A: Feelings about quality of life

Check the answer that best describes how you would feel about being in a coma for the rest of your life.

Life like this would be difficult, but acceptable	Life like this would be worth living, but just barely	Life like this would not be worth living
☐	☐	☐

Part B: Preferences for different life-sustaining treatments

Imagine that while you are in a coma, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will remain in a coma, but the treatment will keep you from dying.

Check an answer for each treatment that best reflects what you would want.	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✔		
Other treatments: (fill in)			

Part C: Reasons for my decisions or other comments

Initials & Date: _______________

Severe Dementia

Imagine you have severe dementia (see pg. 29 for details). This means you:

- cannot think or talk clearly, are confused and no longer recognize family members
- seem uninterested in what's happening around you
- are not in any pain
- are able to walk, but get lost without supervision
- need help with getting dressed, bathing, and bowel and bladder functions

Part A: Feelings about quality of life

Check the answer that best describes how you would feel about having severe dementia <u>for the rest of your life</u>.

Life like this would be difficult, but acceptable	Life like this would be worth living, but just barely	Life like this would <u>not</u> be worth living
☐	☐	☐

Part B: Preferences for different life-sustaining treatments

Imagine that while you have this dementia, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will remain demented, but the treatment will keep you from dying.

Check an answer for each treatment that best reflects what you would want.	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✔	■	■
Other treatments: (fill in)			

Part C: Reasons for my decisions or other comments

Would your answers be different if you seemed happy most of the time? **Yes** **No**

Would your answers be different if you seemed unhappy most of the time? **Yes** **No**

How? ____

____

Initials & Date: ____________

Severe Stroke

Imagine you have had a severe stroke (see pg. 30 for details). This means you:

- are able to think, but your ability to understand what is said to you and communicate with others is severely limited
- have aches and pains that make you uncomfortable most of the time
- are able to walk with a walker, but most of the time you get around in a wheelchair
- need help with getting dressed, bathing, and bowel and bladder functions

Part A: Feelings about quality of life

Check the answer that best describes how you would feel about a severe stroke for the rest of your life.

Life like this would be difficult, but acceptable	Life like this would be worth living, but just barely	Life like this would not be worth living
☐	☐	☐

Part B: Preferences for different life-sustaining treatments

Imagine that in addition to the stroke, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will still have your stroke-related problems, but the treatment will keep you from dying.

Check an answer for each treatment that best reflects what you would want.	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓	■	■
Other treatments: (fill in)			

Part C: Reasons for my decisions or other comments

____

____

____

Initials & Date: ____________

Terminal Illness

Imagine you are expected to die within the next two months (see pg. 31 for details about terminal illness). This means you:

- have days when you drift in and out of awareness
- have a lot of discomfort that requires medication
- are in bed most of the time due to weakness
- need help with getting dressed, bathing, and bowel and bladder functions

Part A: Feelings about quality of life

Check the answer that best describes how you would feel about having a terminal illness.

Life like this would be difficult, but acceptable	Life like this would be worth living, but just barely	Life like this would <u>not</u> be worth living
☐	☐	☐

Part B: Preferences for different life-sustaining treatments

Imagine that in addition to the terminal illness, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will get weaker and die in about 2 months, but the treatment will keep you from dying immediately.

Check an answer for each treatment that best reflects what you would want.

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✔	■	■
Hospice			
Other treatments: (fill in)			

Part C: Reasons for my decisions or other comments

Initials & Date: ____________

A future situation of concern when I might not be able to express my wishes

My doctor has told me that given my particular circumstances, I could end up like (write in a description of possible future situations):

____

____

Part A: Feelings about quality of life

Check the answer that best describes how you would feel about this situation.

Life like this would be difficult, but acceptable	Life like this would be worth living, but just barely	Life like this would not be worth living
☐	☐	☐

Part B: Preferences for different life-sustaining treatments

Imagine that in addition to the situation described above, you develop a life-threatening illness and are unable to communicate. The doctors feel that no matter what treatments you receive, you will still have the problems described above, but the treatments will keep you from dying.

Check an answer for each treatment that best reflects what you would want.

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don’t know/can’t answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✔	■	■
Other treatments: (fill in)			

Part C: Reasons for my decisions or other comments

____

____

____

How to talk about your wishes

How can this section help me?

- Talking about end-of-life issues is often difficult, both for you and your family. We've included some sample scripts to give you specific ideas about how to start and get family and care providers to listen to you.
- This section also gives you tips on how to make sure that your family and health care providers not only hear you, but understand you.
- There is a list of nine issues to discuss, so you'll be sure to cover all the important points.
- The last page has questions and answers about legal and ethical issues to consider as well.

Talking about your wishes.

Perhaps the single most important step in advance care planning is talking about your wishes with whomever might be called upon to speak for you. Whether or not you complete a formal advance directive, you still need to express your preferences clearly to your loved ones and health care providers.

Talking with your loved ones and health care providers can also help you think about what you want. Often they will ask you questions or tell you things that will make you think about your wishes in another way. The more thoroughly and clearly you communicate, the easier it will be for everyone to do the right thing.

Starting the discussion

There is no "right" way to start this conversation. Nor is there a "right" time. The best thing to do is make a time and get started. But what if loved ones resist? What if they make excuses like, “You’ve got a lot of life left in you—why do we have to talk about this now?” Here are some suggestions for getting started:

- **Relate a story from this book.** If there was a story from the first part of this book that got your attention, it may also get the attention of the person you want to talk to. Share this story with them to let them know what you are concerned about and why this is important to you.

- **Remind them of a situation someone else experienced.** Another way to introduce the topic is to think about stories of friends or relatives who experienced an illness and faced a difficult situation. You could start the conversation saying,

“Do you remember what happened to so-and-so and what his family went through? I don’t want you to have to go through that with me. That’s why I want to talk about this <u>*now*</u>*, while we can.”*

- **Be firm and straightforward.** If someone puts you off out of their own discomfort, you could say,

“I know this makes you feel uncomfortable, but I need you to bear with me and hear what I have to say because it’s very important to me.”

- **Point out the possible consequences of not talking now.** Someone may be more willing to talk if you start by saying something like,

“If we don’t talk about this now, we could both end up in a situation that is even more uncomfortable. I’d really like to avoid that if I could.”

- **Use a letter, tape, or video recording.** It may be easier for people to hear what you have to say initially if you aren’t there. So you could ask them to read a personal letter, listen to a tape, or watch a video in which you express your feelings and preferences. Afterwards, they may be more ready to sit down and talk with you.

Asking someone to be your spokesperson

When you ask someone to be your spokesperson, you are asking them to assume a big responsibility that you both want to be comfortable with. To ease into the conversation, you might ask questions like:

"Would you be willing to represent my views about medical decisions if I can't speak for myself?"

"Can you make decisions for me that are based on my values, preferences, and wishes—even if they're not like yours?"

You do not want this person to agree to be your spokesperson if they really have strong misgivings about it. So be sure to tell them that you will not be offended or hurt if they feel they cannot do this for you.

If the person agrees to be your spokesperson, you can reassure them that you are not expecting them to be "superhuman" or all-knowing. Give them explicit permission to make decisions for you, especially for those situations that you haven't discussed or couldn't predict.

Who else should you talk to?

Think about the people who play an important part in your life. Then try to imagine a time when you are either seriously ill or injured and unable to communicate. Who would you want to be around at such a time? These are the people you should make a point of sharing your feelings with now. They might include:

- Your spokesperson
- Health care providers
- Other caregivers
- Family
- Friends
- Clergy

You do not need to speak to everyone at the same time. However, it can be helpful to talk to your family as a group so that they all hear what you have to say in the same way.

What if you don't have close family or friends?

Your best option is to write down your wishes, either in an advance directive or personalized statement, or both. You could also make a tape or video recording of your wishes. Then be sure to share it with your health care providers.

Nine important issues to discuss

We recommend that you talk about the following issues. Discussing them will help avoid confusion, conflict, and hurt feelings between loved ones and care providers.

1. Your Choice of a Spokesperson—Let your loved ones and care providers know who you have chosen to be your spokesperson—and why. This is especially important if your spokesperson is not a member of the family. You might say something like this:

"I've asked so-and-so to be my spokesperson in case I need medical care but can't speak for myself. My choice is not a reflection of my relationship with you. But after careful thought, I feel that he/she is the right person to handle this responsibility for these reasons..."

2. Your Beliefs—Tell those close to you what it is that makes life worth living, as well as what would make it unbearable—and why. If you have fears about being a burden, explore these feelings with those who will care for you. Family members often view caring for loved ones as an honor—not a burden. Use the exercises in this workbook to help you talk about these issues.

3. Health Conditions—Share how you feel about being kept alive in conditions that could leave you unable to speak for yourself.

4. Life-sustaining Treatments—Share how you'd feel about different medical treatments, including hospice, and under what circumstances you would or would not want to receive them.

5. Your Vision Of A Good Death—If you hope to die in a certain way—whether it's at home, in your sleep, with family by your side, or free of pain—tell people.

6. Organ Donation—If you'd like others to benefit from your healthy organs after your death, make sure you family understands this because they *must* give their permission.

7. Funeral Arrangements—Share your thoughts about what you want to be done with your remains. If you have ideas about what you would like for a memorial service or how you'd like an obituary to read, talk about that too.

8. Documentation Of Your Wishes—If you've decided to complete an advance directive or write a personalized statement, tell people where they can find this information in the *future*.

9. Helping others use your personalized directive—Instructional directives and personal statements can be understood either as specific instructions, or as general guidelines. You can help others interpret your written wishes by including something like this in your document:

"I would like the statements in my personalized directive followed to the letter."

"I would like the statements in my personalized directive to be used as a general guide."

"I want those statements that I've marked with a star (*) followed to the letter because I feel very strongly about them. Use the rest of my statements as a general guide."

Talking to your health care providers

Here are a few reasons why it is important to talk to your health care providers about advance care planning:

- They need to know that you've documented your wishes in an advance directive or personalized statement. Without this knowledge, your health care providers could make treatment decisions that may not agree with your wishes.
- You want to be sure that they will interpret your wishes or your advance directive in the way you intend. If they believe your words mean one thing, while your spokesperson or family members interpret it differently, you'll probably get treatment until they can resolve their differences.
- Your health care providers can answer questions you may have about different health conditions, treatments, and your prognosis.

Make a special appointment

To make sure you've got their attention, make a special appointment with your health care provider to talk about this. Health care providers are people too—some are uncomfortable talking about end-of-life issues, or have other things on their mind. You don't want to be in a hurry when you have this conversation.

If your health care provider wants to just file your advance directive in your chart without discussing it, <u>don't let that happen</u>! Make sure they know *why* you feel the way you do. This will make it easier for them to understand and follow your wishes.

What to say

To help you organize your thoughts and cover all the important issues, bring a copy of your advance directive and any exercises you completed from this workbook, particularly those on pages 20-24 and 38-43. Also during this appointment, you may want to ask some or all of these questions:

"Given my current health, am I at risk of facing a situation when I might not be able to communicate?"

"Is there anything about my current health that would compromise the likelihood of success of different treatments?"

"Can I count on you to respect my wishes and contact my spokesperson if I'm unable to speak for myself?"

"What if you're not the health care provider who's there when I need care? How will the other health care providers know about my wishes?"

Reviewing your wishes

With all the advances in medicine and health care, it's a good idea to review your wishes from time to time. Values and preferences for health care often change with age or when there are changes in your health condition. When and how often you review your wishes depends on your circumstances.

Changes in your family situation

If your spokesperson moves, you get a divorce, or a family member dies, you may need to rethink who will speak for you.

When you are healthy

When you're healthy, a periodic review prepares you and your family for emergency situations, such as a car accident or a sudden illness. Here are some ideas about good times to schedule these reviews.

- **Just before an annual check-up with your health care provider.** You'll refresh your memory about what you said last year, and then be ready to talk about new questions or concerns at your appointment.

- **Special anniversary dates.** Some people pick dates such as a birthday or the first day of spring. By picking the same date every year, it gets on your "to do" list and becomes a part of your routine.

- **Holidays or other family gatherings.** Others like to do this during these times so they can take advantage of having everyone together in the same place. This makes it easier to share their views with everyone all at once.

When your health changes

Another important time to think about your wishes is if your health condition changes, especially if it takes a turn for the worse. Here are some things to think about in these circumstances.

- **Adjusting to new limitations.** People often think that if they had physical or mental limitations their life would be terrible. But some people adjust to limitations and disability and find that life still has a lot to offer them. After you've given yourself some time to get used to your new situation, take another look at the exercise on page 21 to see if your thoughts have changed about what makes life worth living.

- **Concerns about being a burden.** It's normal for people with new limitations to feel like they are a burden because they need more help from others. But be sure to ask your family members what it means to them to be a burden before you "spare" them. You may be taking away their chance to return the gift of the love and care that you've given them.

When you are dying

After people learn they are dying, they often rethink their priorities. Their attention often shifts to making the most of the time they have left. The exercise on page 24 can help you focus on what's important at this time.

Legal and ethical issues of advance care planning

Q: *What do I need to do to make sure my advance directive is a legal document?*

A: Generally speaking, you need to sign your advance directive and have it witnessed. There are instructions with the forms in the back pocket that cover the steps you need to take to make your directive a legal document.

Q: *Will my advance directive be legal in all 50 states?*

A: The laws vary from state to state, but most states will recognize the *intent* of an advance directive. If you have a home in more than one state, check with your health care provider or a lawyer in each state—one form might work for all places.

Q: *Do health care providers have to follow my advance directive?*

A: Yes, but if they disagree with the preferences you indicate in your advance directive, they should refer your care to another provider. In a minority of cases, providers have "overruled" patient directives because they felt that the circumstances at the time did not match what was written.

Q: *What if family members and/or providers disagree about how to interpret my directive?*

A: Most health care facilities have an Ethics Committee who can help resolve disagreements between family members or family members and providers. Talking with your caregivers ahead of time can help avoid future conflicts.

Q: *Is withdrawing treatment considered suicide?*

A: Most people would say "no." Withdrawing or stopping a treatment after it has been started, is one way that patients can exercise their right to refuse treatment especially if the treatment does not seem to be achieving the desired goal. However, some religions believe otherwise. You may want to check with your religious advisor to be sure.

Q: *What is the difference between withholding and withdrawing treatment?*

A: From an ethical and legal standpoint, there is no difference between these two: both are ways to stop unwanted or ineffective treatments. However, not all religions agree with this view—again, you should check with your clergy. Also, some people feel it is harder to withdraw treatment once it is started than to withhold it. But having the option to withdraw treatments means that doctors can give treatments a try, then stop them if they aren't working.

Q: *Can I specify that I want assisted suicide in my directive?*

A: No. Assisted suicide is currently illegal. However, even if it becomes legal, the person making the request would have to be competent and able to change their mind at the time of the suicide. Advance directives only go into effect when you are no longer competent to make decisions.

Other Resources

Contact any of the following organizations for more information about topics covered in this workbook. Many of the national organizations have local chapters. Call the numbers listed for a referral to the chapter nearest you. Each organization also has a wealth of information on the World Wide Web, with links to other sites and organizations. Visit them at the internet addresses listed below.

Disease-related groups

Alzheimer's Association
(800) 272-3900
Internet: www.alz.org

American Cancer Society
(800) 227-2345 (800-ACS-2345)
Internet: www.cancer.org

American Diabetes Association
(800) 342-2383 (800-DIABETES)
Internet: www.diabetes.org

American Heart Association
(800) 227-8721 (800-AHA-USA1)
Internet: www.americanheart.org

American Lung Association
(800) 586-4872 (800-LUNGUSA)
Internet: www.lungusa.org

National Kidney Foundation
(800) 622-9010
Internet: www.kidney.org

National Stroke Association
(303) 649-9299
Internet: www.stroke.org

Advance directives

Choice in Dying
(800) 989-9155 (800-989-WILL)
Internet: www.choices.org

Hospice

National Hospice Organization
(703) 243-5900
Internet: www.nho.org

Organ & Tissue Donation

Coalition on Organ & Tissue Donation
(800) 355-7427 (800-355-SHARE)
Internet: www.infi.net/%7Edonation

Funerals & Cremation

National Funeral Directors Association
(800) 228-6332
Internet: www.nfda.org

Neptune Society (cremation)
(800) 201-3315
www.neptunesociety.com

RHODE ISLAND
Advance Directive
Planning for Important Healthcare Decisions

Caring Connections
1700 Diagonal Road, Suite 625, Alexandria, VA 22314
www.caringinfo.org
800/658-8898

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.

Caring Connections tracks and monitors all state and federal legislation and significant court cases related to end-of-life care to ensure that our advance directives are up to date.

It's About How You LIVE

It's About How You LIVE is a national community engagement campaign encouraging individuals to make informed decisions about end-of-life care and services. The campaign encourages people to:

Learn about options for end-of-life services and care
Implement plans to ensure wishes are honored
Voice decisions to family, friends and health care providers
Engage in personal or community efforts to improve end-of-life care

Please call the HelpLine at 800/658-8898 to learn more about the LIVE campaign, obtain free resources, or join the effort to improve community, state and national end-of-life care.

If you would like to make a contribution to help support our work, please visit www.nationalhospicefoundation.org/donate. Contributions to national hospice programs can also be made through the Combined Health Charities or the Combined Federal Campaign by choosing #0544.

**Support for this program is provided by a grant from
The Robert Wood Johnson Foundation, Princeton,
New Jersey.**

Your Advance Care Planning Packet

Using These Materials

BEFORE YOU BEGIN

1. Check to be sure that you have the materials for each state in which you could receive health care.

2. These materials include:
   - Instructions for preparing your advance directive.
   - Your state-specific advance directive forms, which are the pages with the gray instruction bar on the left side.

PREPARING TO COMPLETE YOUR ADVANCE DIRECTIVE

3. Read the HIPAA Privacy Rule Summary on page 4.

4. Read all the instructions, on pages 7 through 9, as they will give you specific information about the requirements in your state.

5. Refer to the Glossary of Terms About End-of-Life Decision-making if any of the terms are unclear, located in Appendix A.

ACTION STEPS

6. You may want to photocopy these forms before you start so you will have a clean copy if you need to start over.

7. When you begin to fill out the forms, refer to the gray instruction bars - they will guide you through the process.

8. Talk with your family, friends, and physicians about your advance directive. Be sure the person you appoint to make decisions on your behalf understands your wishes.

9. Once the form is completed and signed, photocopy the form and give it to the person you have appointed to make decisions on your behalf, your family, friends, health care providers and/or faith leaders so that the form is available in the event of an emergency.

If you have questions or need guidance in preparing your advance directive or about what you should do with it after you have completed it, please refer to the list of state-specific contacts for Legal Assistance for Questions Pertaining to Health Care Advance Directives located in Appendix B.

Summary of the HIPAA Privacy Rule

HIPAA is a federal law that gives you rights over your health information and sets rules and limits on who can look at and receive your health information.

Your Rights

You have the right to:

- Ask to see and get a copy of your health records.
- Have corrections added to your health information.
- Receive a notice that tells you how your health information may be used and shared.
- Decide if you want to give your permission before your health information can be used or shared for certain purposes, such as marketing.
- Get a report on when and why your health information was shared for certain purposes.
- If you believe your rights are being denied or your health information isn't being protected, you can
  - File a complaint with your provider or health insurer
  - File a complaint with the U.S. Government

You also have the right to ask your provider or health insurer questions about your rights. You also can learn more about your rights, including how to file a complaint from the Web site at www.hhs.gov/ocr/hipaa/ or by calling 1-866-627-7748.

Who Must Follow this Law?

- Doctors, nurses, pharmacies, hospitals, clinics, nursing homes, and many other health care providers.
- Health insurance companies, HMOs, most employer group health plans.
- Certain government programs that pay for health care, such as Medicare and Medicaid.

What Information is Protected?

- Information your doctors, nurses, and other health care providers put in your medical record.
- Conversations your doctor has about your care or treatment with nurses and others.
- Information about you in your health insurer's computer system.
- Billing information about you by your clinic / health care provider.
- Most other health information about you held by those who must follow this law.

Summary of the HIPAA Privacy Rule (continued)

Providers and health insurers who are required to follow this law must keep your information private by:

- Teaching the people who work for them how your information may and may not be used and shared.
- Taking appropriate and reasonable steps to keep your health information secure.

To make sure that your information is protected in a way that does not interfere with your health care, your information can be used and shared:

- For your treatment and care coordination.
- To pay doctors and hospitals for your health care and help run their businesses.
- With your family, relatives, friends or others you identify who are involved with your health care or your health care bills, unless you object.
- To make sure doctors give good care and nursing homes are clean and safe.
- To protect the public's health, such as by reporting when the flu is in your area.
- To make required reports to the police, such as reporting gunshot wounds.

Your health information cannot be used or shared without your written permission unless this law allows it. For example, without your authorization, your provider generally cannot:

- Give your information to your employer.
- Use or share your information for marketing or advertising purposes.
- Share private notes about your mental health counseling sessions.

Introduction to Your Rhode Island Advance Directive

This packet contains two legal documents that protect your right to refuse medical treatment you do not want, or to request treatment you do want, in the event you lose the ability to make decisions yourself:

1. The **Rhode Island Durable Power of Attorney for Health Care** lets you name someone to make decisions about your medical care – including decisions about life support – if you can no longer speak for yourself. The Durable Power of Attorney for Health Care is especially useful because it appoints someone to speak for you any time you are incapacitated, not only at the end of life.

2. The **Rhode Island Declaration** is your state's living will. It lets you state your wishes about medical care in the event that you develop an incurable or irreversible condition and can no longer make your own medical decisions. The Declaration becomes effective if, in your doctor's opinion, your death would occur without the use of life-sustaining medical care.

Caring Connections recommends that you complete both of these documents to best ensure that you receive the medical care you want when you can no longer speak for yourself.

Note: These documents will be legally binding only if the person completing them is a competent adult (at least 18 years old).

Completing Your Rhode Island Durable Power of Attorney fro Health Care

Whom should I appoint as my agent?

Your agent is the person you appoint to make decisions about your medical care if you become unable to make those decisions yourself. The person you name as your agent should clearly understand your wishes and be willing to accept the responsibility of making medical decisions for you. Your agent may be a family member or a close friend whom you trust to make serious decisions. (An agent may also be called an "attorney-in-fact" or "proxy.")

The person you appoint as your agent **cannot** be:

- your treating health care provider,
- an employee of your treating health care provider who is not related to you,
- an operator of a community care facility, or
- an employee of an operator of a community care facility who is not related to you.

You can appoint a second and third person as alternate agents. The alternates will step in, by order of selection, if the first person you name as agent is unable, ineligible or unavailable to act for you. If you appoint your spouse as your agent, he or she will become ineligible to act as your agent if your marriage is dissolved.

How do I make my Rhode Island Durable Power of Attorney for Health Care legal?

The law requires that you sign and date your Durable Power of Attorney for Health Care in the presence of two witnesses or one notary public. The witnesses sign the document to show that they know you and believe you to be of sound mind and under no duress, fraud or undue influence, that you signed or acknowledged the signature of the document in their presence, and that they do not fall into any of the categories of people who cannot be witnesses.

These witnesses **cannot** be:

- the person you name as your agent or alternate agent(s),
- a health care provider,
- an employee of a health care provider,
- the operator of a community care facility, or
- an employee of an operator of a community care facility.

At least one of your witnesses or the notary public cannot be related to you by blood, marriage or adoption, or be entitled to any part of your estate under an existing will or by operation of law.

Note: You do not need to notarize your Rhode Island Durable Power of Attorney for Health Care if it is signed by two qualified witnesses.

Completing Your Rhode Island Durable Power of Attorney fro Health Care (continued)

Should I add personal instructions to my Rhode Island Durable Power of Attorney for Health Care?

Caring Connections advises you not to add instructions to this document. One of the strongest reasons for naming an agent is to have someone who can respond flexibly as your medical situation changes and deal with situations that you did not foresee. If you add instructions to this document, you might unintentionally restrict your agent's power to act in your best interest. A statement such as, "My agent knows my wishes concerning all forms of medical treatment" is sufficient. Then, we urge you to talk with your agent about your future medical care and describe what you consider to be an acceptable "quality of life." If you want to record your wishes about specific treatments or conditions, you should use the Rhode Island Declaration (the living will).

What if I change my mind?

You may revoke your Rhode Island Durable Power of Attorney for Health Care at any time and in any manner, regardless of your mental or physical condition. Your revocation becomes effective once you, or a witness to your revocation, communicate it to your doctor or any health care provider, who must then make it part of your medical record.

What other important facts should I know?

Due to restrictions in the state law, a pregnant patient's Rhode Island Durable Power of Attorney for Health Care will not be honored if it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining procedures.

Completing Your Rhode Island Declaration

How do I make my Declaration legal?

In order to make your Declaration legally binding, you must sign your Declaration in the presence of two witnesses, who must also sign the document to show that they personally know you, that you voluntarily signed the document in their presence, and that they are not related to you by blood or marriage.

Note: You do not need to notarize your Rhode Island Declaration.

The Declaration becomes effective when it is communicated to your doctor, the doctor determines that you are in a terminal condition and you are unable to make treatment decisions.

Can I add personal instructions to my Declaration?

Yes. You can add personal instructions in the part of the document called "Other directions." For example, you may want to refuse specific treatments by a statement such as, "I especially do not want cardiopulmonary resuscitation, tube feeding, a respirator, or antibiotics." You may also want to emphasize pain control by adding instructions such as, "I want to receive as much pain medication as necessary to ensure my comfort, even if it may hasten my death."

If you have appointed an agent, it is a good idea to write a statement such as, "Any questions about how to interpret or when to apply my Declaration are to be decided by my agent."

It is important to learn about the kinds of life-sustaining treatment you might receive. Consult your doctor or order the Caring Connections booklet, "Advance Directives and End-of-Life Decisions."

What if I change my mind?

You can revoke your Rhode Island Declaration at any time and in any manner, regardless of your physical or mental condition. Your revocation becomes effective once you, or a witness to your revocation, notify your doctor or health care provider, who must then make the revocation part of your medical record.

What other important facts should I know?

Due to restrictions in the state law, a pregnant patient's Rhode Island Declaration will not be honored if it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining procedures.

If you have questions about filling out your advance directive, please consult the list of state-based resources located in Appendix B.

You Have Filled Out Your Advance Directive, Now What?

1. Your Rhode Island Durable Power of Attorney for Health Care and Rhode Island Declaration are important legal documents. Keep the original signed documents in a secure but accessible place. Do not put the original documents in a safe deposit box or any other security box that would keep others from having access to them.

2. Give photocopies of the signed originals to your agent and alternate agent(s), doctor(s), family, close friends, clergy and anyone else who might become involved in your health care. If you enter a nursing home or hospital, have photocopies of your documents placed in your medical records.

3. Be sure to talk to your agent and alternates, doctor(s), clergy, and family and friends about your wishes concerning medical treatment. Discuss your wishes with them often, particularly if your medical condition changes.

4. If you want to make changes to your documents after they have been signed and witnessed, you must complete new documents.

5. Remember, you can always revoke one or both of your Rhode Island documents.

6. Be aware that your Rhode Island documents will not be effective in the event of a medical emergency. Ambulance personnel are required to provide cardiopulmonary resuscitation (CPR) unless they are given a separate order that states otherwise. These orders, commonly called “non-hospital do-not-resuscitate orders,” are designed for people whose poor health gives them little chance of benefiting from CPR. **Caring Connections does not distribute these forms.**

   These orders must be signed by your physician and instruct ambulance personnel not to attempt CPR if your heart or breathing should stop. Currently not all states have laws authorizing non-hospital do-not-resuscitate orders. **Caring Connections does not distribute these forms.** We suggest you speak to your physician.

   If you would like more information about this topic contact Caring Connections or consult the Caring Connections booklet “Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders and End-Of-Life Decisions.”

RHODE ISLAND STATUTORY FORM
DURABLE POWER OF ATTORNEY FOR HEALTH CARE – PAGE 1 OF 7

WARNING TO PERSON EXECUTING THIS DOCUMENT
(R.I. Gen. Laws 23-4.10-1 to 23-4.10-2 [1989])

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 of Rhode Island 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 except to inform your next of kin of your desire to be an organ and tissue donor.

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.

INSTRUCTIONS

RHODE ISLAND STATUTORY FORM DURABLE POWER OF ATTORNEY FOR HEALTH CARE

1. DESIGNATION OF HEALTH CARE AGENT.

PRINT YOUR NAME AND ADDRESS

I, ____,
(name)

_ _
(address)

PRINT THE NAME, ADDRESS, AND TELEPHONE NUMBERS OF YOUR AGENT

do hereby designate and appoint:

____
(name of agent)

_ _
(address)

_ _
(home telephone number) (work telephone number)

(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 non-relative employee of your treating health care provider, (3) an operator of a community care facility, or (4) a non-relative 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 and informing my family or next of kin of my desire, if any, to be an organ or tissue donor. *(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:

ADD PERSONAL INSTRUCTIONS (IF ANY)

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

ADD PERSONAL INSTRUCTIONS (IF ANY)

b. Additional statements 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.)

ORGAN DONATION (INITIAL IF APPLICABLE)

If you wish to make a gift of any bodily organ you may do so pursuant to the Uniform Anatomical Gift Act.

____ I want to be an organ donor. In the event of my death I request that my agent inform my family/next of kin of my desires to be an organ and tissue donor if possible. My wishes are indicated below.

I wish to give:
____ any needed organs/ tissues: or
____ only the following organs/tissues:______________________________

____

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.

PRINT EXPIRATION DATE OF YOUR DURABLE POWER OF ATTORNEY (OPTIONAL)

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.)

ALTERNATE AGENTS

PRINT THE NAME, ADDRESS AND TELEPHONE NUMBER OF TWO ALTERNATE AGENTS

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:

____

ALTERNATE #1

_ _

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

B. Second Alternate Agent:

ALTERNATE #2

____

_ _

(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 YOUR DOCUMENT AND PRINT YOUR CITY AND STATE OF RESIDENCE

SIGN YOUR DOCUMENT HERE

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 ________________________ at ________________________,
(date) (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.) YOU ARE NOT REQUIRED TO HAVE THIS POWER OF ATTORNEY NOTARIZED

WITNESSING PROCEDURE

YOUR WITNESSES MUST DATE AND SIGN YOUR DOCUMENT ON THE NEXT PAGE THEY MUST ALSO PRINT THEIR NAMES AND ADDRESSES

STATEMENT OF WITNESSES

(This document must be witnessed by two (2) qualified adult witnesses or one (1) notary public. 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 or the notary public 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.

WITNESS #1

Signature:

____

Print Name: _

Residence Address:

____

_ _

Date: ___________________

WITNESS #2

Signature:

____

Print Name: _

Residence Address:

____

_ _

Date: ___________________

ONE WITNESS MUST AGREE WITH THIS STATEMENT AND SIGN AND PRINT HIS OR HER NAME BELOW

(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:

____

Courtesy of Caring Connections

RHODE ISLAND DECLARATION – PAGE 1 OF 2

INSTRUCTIONS

PRINT YOUR
NAME

ADD PERSONAL
INSTRUCTIONS
(IF ANY)

CHECK THE
OPTION THAT
REFLECTS
YOUR WISHES

SIGN AND DATE
THE DOCUMENT
AND PRINT
YOUR ADDRESS

I,
____,
(name)
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, without the administration of life-sustaining procedures, will cause my death, 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.

Other directions:

This authorization _______ includes _______ does not include the withholding or withdrawal of artificial feeding. (check only one option)

Signed this ___________ day of ______________________, 20
(date) (month)

______________.
(year)

Signature _

Address _

WITNESSING PROCEDURE

YOUR WITNESSES MUST SIGN AND PRINT THEIR ADDRESSES

RHODE ISLAND DECLARATION - PAGE 2 OF 2

The declarant is personally known to me and voluntarily signed this document in my presence. I am not related to the declarant by blood or marriage.

Witness

____

Address

____

Witness

____

Address

____

Courtesy of Caring Connections
1700 Diagonal Road, Suite 625, Alexandria, VA 22314
www.caringinfo.org, 800/658-8898

Appendix A

Glossary of Terms About End-of-life Decision Making

Advance directive - A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

Artificial nutrition and hydration – Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein.

Assisted Suicide - Providing someone the means to commit suicide, such as a supply of drugs or a weapon, knowing the person will use these to end his or her life.

Best Interest - In the context of refusal of medical treatment or end-of-life court opinions, a standard for making health care decisions based on what others believe to be "best" for a patient by weighing the benefits and the burdens of continuing, withholding or withdrawing treatment.

Brain Death -The irreversible loss of all brain function. Most states legally define death to include brain death.

Capacity - In relation to end-of-life decision-making, a patient has medical decision making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court.

Cardiopulmonary Resuscitation - Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart.

Do-Not-Resuscitate (DNR) order - A DNR order is a physician's written order instructing health care providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

***Emergency Medical Services (EMS)*:** A group of governmental and private agencies that provide emergency care, usually to persons outside of health care facilities; EMS personnel generally include paramedics, first responders and other ambulance crew.

Euthanasia - The term traditionally has been used to refer to the hastening of a suffering person's death or "mercy killing". Voluntary active euthanasia involves an intervention requested by a competent individual that is administered to that person to cause death, for example, if a physician gives a lethal injection with the patient's full informed consent. Involuntary or non-voluntary active euthanasia involves a physician engaging in an act to end a patient's life without that patient's full informed consent. See also Physician-hastened Death (sometimes referred to as Physician-assisted Suicide).

Guardian ad litem - Someone appointed by the court to represent the interests of a minor or incompetent person in a legal proceeding.

***Healthcare Agent*:** The person named in an advance directive or as permitted under state law to make healthcare decisions on behalf of a person who is no longer able to make medical decisions.

Hospice care - A program model for delivering palliative care to individuals who are in the final stages of terminal illness. In addition to providing palliative care and personal support to the patient, hospice includes support for the patient's family while the patient is dying, as well as support to the family during their bereavement.

Incapacity - A lack of physical or mental abilities that results in a person's inability to manage his or her own personal care, property or finances; a lack of ability to understand one's actions when making a will or other legal document.

Incompetent – Referring to a person who is not able to manage his/her affairs due to mental deficiency (lack of I.Q., deterioration, illness or psychosis) or sometimes physical disability. Being incompetent can be the basis for appointment of a guardian or conservator.

Intubation- Refers to "endotracheal intubation" the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

***Life-Sustaining Treatment* -** Treatments (medical procedures) that replace or support an essential bodily function (may also be called life support treatments). Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis, and certain other treatments.

Living Will - A type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate. It may also be called a "directive to physicians", "health care declaration," or "medical directive." The purpose of a living will is to guide family members and doctors in deciding how aggressively to use medical treatments to delay death.

Mechanical ventilation - Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease.

Medical power of attorney - A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. This type of advance directive may also be called a health care proxy, durable power of attorney for health care or appointment of a health care agent. The person appointed may be called a health care agent, surrogate, attorney-in-fact or proxy.

Palliative care - A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, by controlling pain and symptoms, and by enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values are an essential component. Palliative care is sometimes called "comfort care" or "hospice type care."

Power of Attorney – A legal document allowing one person to act in a legal matter on another's behalf pursuant to financial or real estate transactions.

Respiratory Arrest**:** The cessation of breathing - an event in which an individual stops breathing. If breathing is not restored, an individual's heart eventually will stop beating, resulting in cardiac arrest.

Surrogate Decision-Making - Surrogate decision-making laws allow an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an advance directive. A majority of states have passed statutes that permit surrogate decision making for patients without advance directives.

Ventilator – A Ventilator, also known as a respirator, is a machine that pushes air into the lungs through a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own or cannot breathe effectively enough to provide adequate oxygen to the cells of the body or rid the body of carbon dioxide.

Withholding or withdrawing treatment - Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.

Appendix B

Legal & End-Of-Life Care Resources Pertaining to Health Care Advance Directives

LEGAL SERVICES

The State Rhode Island Department of Elder Affairs provides legal services for individuals 60 and older with low to moderate incomes.

They can assist anyone over 60 with legal information and advice on most issues, including:

- Nursing homes
- Advance Directives
- Living Wills and Trusts
- Power of Attorney and more

For more information please call toll free: 1-800-662-5034

OR

Visit their website for other referrals and information:
http://www.dea.state.ri.us/programs/legal_assist.php

ENND-OF-LIFE SERVICES

Individuals over the age 60 with low to moderate incomes can visit Rhode Island Department of Elder Affairs website for services in their area.

They provide resources and services including, but not limited to:

- Housing
- Prescription drug programs
- Medicare and Medicaid
- Legal assistance
- Meals and transportation
- Programs, services and more

- Must be 60 and older
- Free for individuals with low to moderate incomes

For more information about services call:
1-401-462-0740 or 1-401-462-4000

OR

Visit their website for information about other services and programs:
http://www.dea.state.ri.us/programs/

PUT IT IN WRITING

Questions and Answers on Advance Directives

American Hospital Association

www.aha.org

July 1998, Revised April 2005, Item No. 166909

Many people today are worried about the medical care they would be given if they should become terminally ill and unable to communicate their wishes. They don't want to spend months or years dependent on life-support machines, and they don't want to cause unnecessary emotional or financial distress for their loved ones.

That's why a growing number of people are taking an active role in their care before they become seriously ill. They are stating their health care preferences in writing, while they are still healthy and able to make such decisions, through legal documents called advance directives.

Before deciding what choices about your care at the end of life are best, you should talk over the issues involved with your family and your physician. Find out about the laws and forms that apply in your state. Decide whether advance directives are right for you.

This brochure will give you some basic facts about advance directives to get you started on this process.

Advance Directives

Questions & Answers

Q What are advance directives?

A Formal advance directives are documents written in advance of serious illness that state your choices for health care, or name someone to make those choices, if you become unable to make decisions. Through advance directives, such as living wills and durable powers of attorney for health care, you can make legally valid decisions about your future medical treatment.

Q Why is there so much interest in advance directives now?

A Questions about medical care at the end of life are of great concern today, partly because of the growing ability of medical technology to prolong life and partly because of highly publicized legal cases involving comatose patients whose families wanted to withdraw treatment. Many people want to avoid extending personal and family suffering by artificial prolongation of life if they are in a vegetative state or when there is no hope of recovery.

The best way for you to retain control in such a situation is to record your preferences for medical care in advance and share your decisions with your physician, loved ones and clergyman.

Q What does the law say about this issue?

A Laws differ somewhat from state to state, but in general a patient's expressed wishes will be honored. No law or court has invalidated the concept of advance directives, and an increasing number of statutes and court decisions support it. In 1990 the U.S. Supreme Court found in the case of Nancy Cruzan that the state of Missouri could require "clear and convincing" evidence of a patient's wishes in order to remove life supports. Formal advance directives can be critical to establishing such clear and convincing evidence of a patient's wishes. The Patient Self-Determination Act of 1990 requires hospitals to inform their patients about advance directives.

Q WHAT IS A LIVING WILL?

A A living will is a document in which you can stipulate the kind of life-prolonging medical care you want if you become terminally ill, permanently unconscious, or in a vegetative state and unable to make your own decisions. Many states have their own living-will forms, each with somewhat different requirements. It is also possible to complete and sign a standard form from a stationery store, draw up your own form, or simply write a statement of your preferences for treatment, as long as you follow the state's witnessing requirements.

A living will should be signed, dated, and witnessed by two people, preferably individuals who know you well but are not related to you and are not your potential heirs or your health care providers. A number of states require a notary or permit a notary in lieu of two witnesses. The living will should be discussed and shared with your physician, family and clergy, and you should ask your physician to make it a part of your permanent medical record. Verify that the living will is indeed in your medical record, including your hospital chart. Although you do not need a lawyer to draw up a living will, you may wish to discuss it with a lawyer and leave a copy with the family lawyer.

Q WHAT IS A DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

A A durable power of attorney for health care is another kind of advance directive: a signed, dated, and witnessed document naming another person to make medical decisions for you if you are unable to make them for yourself at any time, not just at the end of life. You can include instructions about any treatment you want or wish to avoid, such as surgery or artificial nutrition and hydration. The majority of states have specific laws allowing a health care power of attorney, and provide suggested forms. You can draw up a durable power of attorney for health care with or without the advice of a lawyer; however most states do not allow the appointed agent to act as a witness.

Q WHICH IS BETTER-A LIVING WILL OR A DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

A Historically, living wills were developed first, and health care powers of attorney were designed later to be more flexible and apply to more situations. Today the distinction between the two types of documents is becoming blurred. It is possible to have both a living will and a durable power of attorney for health care. Some states combine them in a single document that both describes one's treatment preferences in a variety of situations and names a proxy.

Q HOW CAN I KNOW IN ADVANCE WHICH PROCEDURES I WOULD WANT OR NOT WANT TO PROLONG MY LIFE?

A Although it isn't possible to specify every possible procedure under every possible circumstance, it is possible to decide what kind of treatment you would want in most situations. There are certain common conditions (terminal, irreversible brain damage and dementing illnesses) and treatments commonly used in end-of-life situations (CPR, ventilators, artificial nutrition and hydration, dialysis and antibiotics) that can be discussed in advance.

Preferences can be clarified by thinking about and discussing with your family, friends and others your views about death, being totally dependent on the care of others, the role of family finances, the conditions that would make life intolerable to you, and how artificial life-support would affect the dying process. If you have questions about the kinds of procedures that are often used when illness is severe and recovery unlikely, ask your physician. It is never too early to start this decision-making process, and you should not postpone it until you face serious illness. Patients need to play an active role in determining their own health care decisions.

Q WHAT IS THE LEGAL STATUS OF ADVANCE DIRECTIVES?

A All states legally recognize some form of advance medical directive. Even if a particular instruction in an advance directive might not be enforceable under some circumstances, it is better to express your wishes and intent in some kind of written document than not to express them at all.

Q WHAT IF I DRAW UP A LIVING WILL OR HEALTH CARE POWER OF ATTORNEY AND THEN CHANGE MY MIND?

A You may change or revoke these documents at any time. Any alterations and any written revocation should be signed and dated, and copies should be given to your family, physician, and other appropriate people. (For substantial changes, a new living will should be written and witnessed.) Even without an official written change, your orally expressed direction to your physician generally has priority over any statement made in a living will or power of attorney as long as you are able to decide for yourself and can communicate your wishes. If you wish to revoke an advance directive at any time, you should notify your primary physician, family, clergyman, and others who might need to know. If you consulted an attorney in drawing up your document, you should also notify him or her.

Q WHAT IF I FILL OUT AN ADVANCE DIRECTIVE IN ONE STATE AND AM HOSPITALIZED IN A DIFFERENT STATE?

A The majority of states have reciprocity provisions. Even in those states that do not explicitly address the issue, there is a common law and constitutional right to accept or refuse treatment that may be broader than the rights identified under the state law. Because an advance directive is an expression of your intent regarding your medical care, it will influence that care no matter where you are hospitalized. However, if you spend a great deal of time in more than one state you might wish to consider executing an advance directive in those states.

Q IF A COMATOSE OR MENTALLY INCOMPETENT PATIENT DOESN'T HAVE A LIVING WILL OR DURABLE POWER OF ATTORNEY, WHO DECIDES WHETHER TO WITHDRAW TREATMENT?

A If there is no advance directive by the patient, the decision is left to the patient's family, physician, and hospital, and ultimately a judge. Usually the family, physician, and hospital can reach an agreement without resorting to the courts, often with the help of a hospital ethics committee. However, many times the individual who has the authority to make the decision is not the person the patient would have chosen. There also may be more restrictions on a surrogate than an appointed agent.

Q WHAT WILL THE HOSPITAL DO TO HELP IF I OR MY FAMILY MEMBER SHOULD BE IN THIS SITUATION?

A Many hospitals have ethics committees or ethics consultation services, one of whose functions is to help in decision making about the end of life. Physicians, nurses, social workers, lawyers, clergy, patient representatives, and sometimes professional bioethicists discuss issues, advise on hospital policy, and review cases if there is a conflict or lack of clarity. Although they will often counsel a patient's family and make a recommendation, the final decision is still up to the patient, the family, and the physician.

Q WHERE CAN I GET LIVING-WILL AND HEALTH-CARE-POWER-OF-ATTORNEY FORMS?

A **Caring Connections**
National Hospice & Palliative Care Organization
1700 Diagonal Road, Suite 625
Alexandria, VA 22314
1-800-658-8898

Through their web site www.caringinfo.org, the National Hospice and Palliative Care Organization (NHPCO) offers free, state specific advance directives and advice for communicating wishes to family and close friends. The site is focused around learning, implementing, voicing and engaging in the care you receive at the end-of-life. Information is also available from the American Hospital Association (www.putitinwriting.org), the AARP (www.aarp.org), Aging with Dignity (www.agingwithdignity.org), your state or local Office on Aging, your local bar association, and many local civic and service organizations.

GLOSSARY

Advance Directives

ADVANCE DIRECTIVE	A document in which a person either states choices for medical treatment or designates who should make treatment choices if the person should lose decision-making capacity. The term can also include oral statements by the patient.
ARTIFICIAL NUTRITION AND HYDRATION	A method of delivering a chemically-balanced mix of nutrients and fluids when a patient is unable to eat or drink. The patient may be fed through a tube inserted directly into the stomach, a tube put through the nose and throat into the stomach, or an intravenous tube.
CARDIOPULMONARY RESUSCITATION (CPR)	A medical procedure, often involving external chest compression, administration of drugs, and electric shock, used to restore the heartbeat at the time of a cardiac arrest.
DECISION-MAKING CAPACITY	The ability to make choices that reflect an understanding and appreciation of the nature and consequences of one's actions.
DECLARATION	One type of advance directive, commonly referred to as a living will.
DNR	Do Not Resuscitate; a medical order to refrain from cardiopulmonary resuscitation if a patient's heart stops beating.
DURABLE POWER OF ATTORNEY FOR HEALTH CARE (DPOA)	An advance directive in which an individual names someone else (the "agent" or "proxy") to make health care decisions in the event the individual becomes unable to make them. The DPOA can also include instructions about specific possible choices to be made.
HOSPICE	A program that provides care for the terminally ill in the form of pain relief, counseling, and custodial care, either at home or in a facility.

Legal Guardian	A person charged (usually by court appointment) with the power and duty of taking care of and managing the property and rights of another person who is considered incapable of administering his or her own affairs.
Life-Sustaining Treatment	A medical intervention administered to a patient that prolongs life and delays death.
Palliative Care	Medical interventions intended to alleviate suffering, discomfort, and dysfunction but not to cure (such as pain medication or treatment of an annoying infection).
Persistent Vegetative State	As defined by the American Academy of Neurology, “a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic sleep/wake cycles but at no time is aware of himself or his environment.”
Proxy	A person appointed to make decisions for someone else, as in a durable power of attorney for health care (also called a surrogate or agent).
Terminal Condition	In most states, a status that is incurable or irreversible and in which death will occur within a short time. There is no precise, universally accepted definition of “a short time,” but in general it is considered to be less than one year.
Ventilator	A machine that moves air into the lungs for a patient who is unable to breathe naturally.

NOTES

CFC
COMBINED FEDERAL CAMPAIGN

HFA
HOSPICE FOUNDATION
OF AMERICA

A MEMBER ORGANIZATION OF
Health
& MEDICAL RESEARCH
CHARITIES OF AMERICA

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800-854-3402

e-mail: info@hospicefoundation.org • www.hospicefoundation.org

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Hospice

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> *The thought that you or someone you love is dying can be devastating.*
>
> *It may seem that there is nothing more you can do.*
>
> *But in fact much can be done and Hospice can help.*

contents

what is *Hospice?*

The term "hospice" originated in medieval times when it was used to describe a place of shelter and rest for weary or sick travelers on long journeys. The modern hospice movement began in 1967 when Dr. Cicely Saunders, a British physician, established St. Christopher's Hospice near London. Her program included a team of professional caregivers for each patient, and was the first to combine compassionate care for the dying, which hospice has always offered, with modern pain and symptom control techniques.

Today hospice care is for the patient whose illness is no longer responding to aggressive curative therapies. Hospice addresses all the symptoms of the disease with special emphasis on controlling the patient's pain and discomfort. Hospice also deals with the emotional, social, and spiritual impact of the disease on the patient, and the patient's family and significant others.

A hospice team consists of physicians, nurses, aides, social workers, spiritual caregivers, counselors, therapists, and volunteers: all of whom are specially trained to provide pain and symptom management for the patient and support for the family. The patient and family make up the core of the hospice team and are at the center of all decision making.

The goal of all hospice programs is to improve the quality of the patient's last days and weeks of life by offering comfort and dignity.

To do this, the hospice conducts an evaluation of the patient's physical condition, pain, support system, and environment. Because each patient's/family's needs are unique, a hospice team works with the patient and family to develop a personalized care plan. The delivery of the plan by an interdisciplinary team distinguishes hospice care from ordinary home care.

The hospice brings this caring team right to the patient's home, be it a house, apartment, nursing home, assisted living setting, or residential hospice.

Family members are encouraged to participate in the care by visiting regularly, bringing favorite music or food, and by providing as much hands-on support as is comfortable, such as feeding, bathing, reading favorite books, or just being present.

When care is delivered in the patient's house or apartment the hospice provides instruction, assistance, and support for the family. When hospice care is delivered in a facility, much attention is paid to making the environment and care planning as patient-friendly as possible.

Always, the focus is on controlling pain, managing symptoms, and providing comfort, dignity, and quality of life.

why choose *Hospice?*

Approximately 885,000 people in the United States were cared for by hospice programs in 2002 and the number grows annually. The reasons vary, but those generally identified are simple:

Hospice does not seek to lengthen life nor hasten death, but instead to focus on quality of life.

Hospice workers provide the patient and family with information and opportunities to participate in the decision making process, and focus the care on symptom management, comfort, dignity, and quality of life.

Hospice staff and volunteers assist with all the traditional physical care tasks, such as bathing, managing pain medications, arranging medical equipment, and therapies. The staff and volunteers also do things as simple as provide back rubs, assist with household chores, help put financial matters in order, talk openly about feelings, arrange transportation to doctor appointments, and help family members cope.

Care for the terminally ill in the home generally provides patients more privacy and control of their environment, such as when to eat, what to eat, when to bathe, when to have company, visits with pets, etc. It is also more convenient for family and friends to visit the patient at home.

Many hospice facilities provide this same control and comfort for hospice patients and their significant others.

Data shows that care in the home is less costly than care in a hospital.

The family receives bereavement care for at least one year.

The patient, family, and/or physician can initiate an information/referral call or visit as soon as a terminal disease is diagnosed, or at the same time a patient decides to move from a treatment plan focused on curing the disease to a plan focused on providing comfort and pain relief.

Hospice *services*

Before providing care, a hospice clinician, the patient's personal physician(s), and the hospice physician confer on the patient's disease history, current physical systems, and life expectancy.

A hospice representative meets with the patient and family to discuss the hospice philosophy of care, services available, pain and comfort levels, expectations, Advanced Directives, the support system available, financial and insurance resources, medications, and equipment needs. Patients are asked to sign an informed consent for care. From the information gathered, a "plan of care" is developed. As the patient's condition changes, this plan is regularly reviewed and revised.

The plan of care provides the hospice staff, the patient, and the family with details about what services and support visits (nurse, social worker, aide, counselor, spiritual care, and volunteer) to expect, in addition to what medications, therapies, supplies, and equipment will be used. It also outlines what training the patient and family can expect and how they will participate in the care.

Caregivers are generally asked to provide a safe, comfortable environment, help with feeding, bathing, turning, and giving medications. Caregivers are also advised to alert the hospice of any changes in the patient's condition.

Additionally, the plan of care includes bereavement service needs, for hospice also provides support for caregivers following the patient's death.

interesting facts

unit of care

The patient and family is the "unit of care." Family is defined as relatives, a life partner, and any friends patients view as part of their support network.

Whenever possible, patients are cared for in their own, or a family member's, home.

Volunteers who receive special training take an active role in providing care and support for patients and families and hospice functions. Approximately 400,000 people volunteer for hospice annually.

Hospice staff is available by telephone to provide support 24 hours a day.

In 2002, 50% of hospice patients had a cancer diagnosis. Heart disease, dementia, lung, kidney, and liver disease accounted for 30%, with AIDS and other diseases making up the balance.

There are more than 3,200 hospices in the United States and Puerto Rico.

who *regulates* Hospice care

Most states require hospices to be licensed. The Centers for Medicare and Medicaid Services (CMS) certify hospices that provide Medicare covered services. Medicaid certification is offered in 45 states and the District of Columbia.

The Joint Commission for Accreditation of Health Care Organizations accredits hospices.

Hospice

when *selecting* a Hospice, ask...

- Does the hospice serve your area?
- Is the hospice licensed (where applicable) and Medicare/Medicaid certified?
- Does the hospice provide the services you want/need?
- What does that hospice expect from you and your caregiver support system?
- Will your insurance plan work with the hospice?
- Does the hospice have a support program for caregivers?
- Where is needed inpatient or respite care provided?
- Is the hospice's position on resuscitation, hydration, and antibiotics consistent with yours?
- What out-of-pocket expenses should you anticipate?
- Is there a sliding scale payment plan for services not covered by insurance?

1-800-854-3402

how to find a Hospice in *your* area:

Ask your physician. Check the yellow pages under “Hospice.” On the Internet visit - www.hospicefoundation.org or www.nhpco.org/custom/directory. Call Hospice Foundation of America at 1-800-854-3402 or call the National Hospice and Palliative Care Organization at 1-800-658-8898.

who *pays* for Hospice care?

Medicare has a Hospice Benefit for patients with a prognosis of six months or less if the disease runs its normal course. The Medicare Benefit is covered for longer than six months if the patient is re-certified as being terminally ill.

This benefit covers all the services, medications, and equipment related to the terminal illness. These include: physician direction, intermittent nursing services, home health aides and homemakers, social workers, spiritual caregivers, volunteers, physical, occupational, and speech therapists, medications for pain and symptom management, medical supplies and equipment, short term inpatient care for crisis management and respite care, continuous home care in times of crisis, and bereavement services for the family up to a year following the patient’s death. In certain cases, such as equipment and pharmacy, a small co-payment may be applied.

- 45 states and the District of Columbia offer Medicaid covered hospice services.
- Most insurance plans and managed care plans cover hospice.
- Hospice services are covered under Tricare, the health benefits program for the military.
- A patient receiving the Medicare Hospice Benefit will continue their regular Medicare coverage for other illnesses, diseases, or care.

Hospice Foundation *of* America

Hospice Foundation of America (HFA) is a grassroots, non-profit organization that acts as an advocate for the hospice concept of care by training health care workers and the families they serve on issues related to terminal illness and loss, providing information to the public about end-of-life care, and supporting programs designed to encourage the extension of hospice care to persons of all ages and illnesses.

Hospice Foundation of America offers programs and publications that assist caregivers to serve the terminally ill and their grieving loved ones:

- Distance learning and continuing education for health care professionals is offered through Hospice College of America, a subsidiary of Hospice Foundation of America
- The Living With Grief® teleconference series, which provides free bereavement education and assistance to over 100,000 professionals and lay people annually through North America
- Journeys, a monthly newsletter that offers support for those coping with loss
- Training programs for clergy in ministering to families in medical crises
- “Clergy to Clergy,” an audiotape series designed to help clergy minister more effectively to others
- Resources for the military and civilian communities to help them respond to loss
- Opportunities for the chronically and terminally ill to tell the stories of their lives through A Guide for Recalling and Telling Your Life Story
- The Living With Grief textbook series
- Information and guidance to companies on handling grief in the workplace