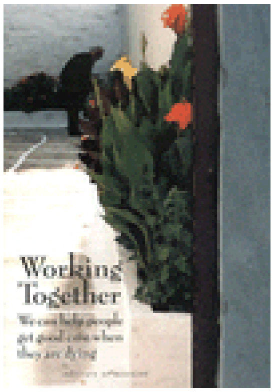

Working Together: We Can Help People Get Good Care When They Are Dying

Institute of Medicine

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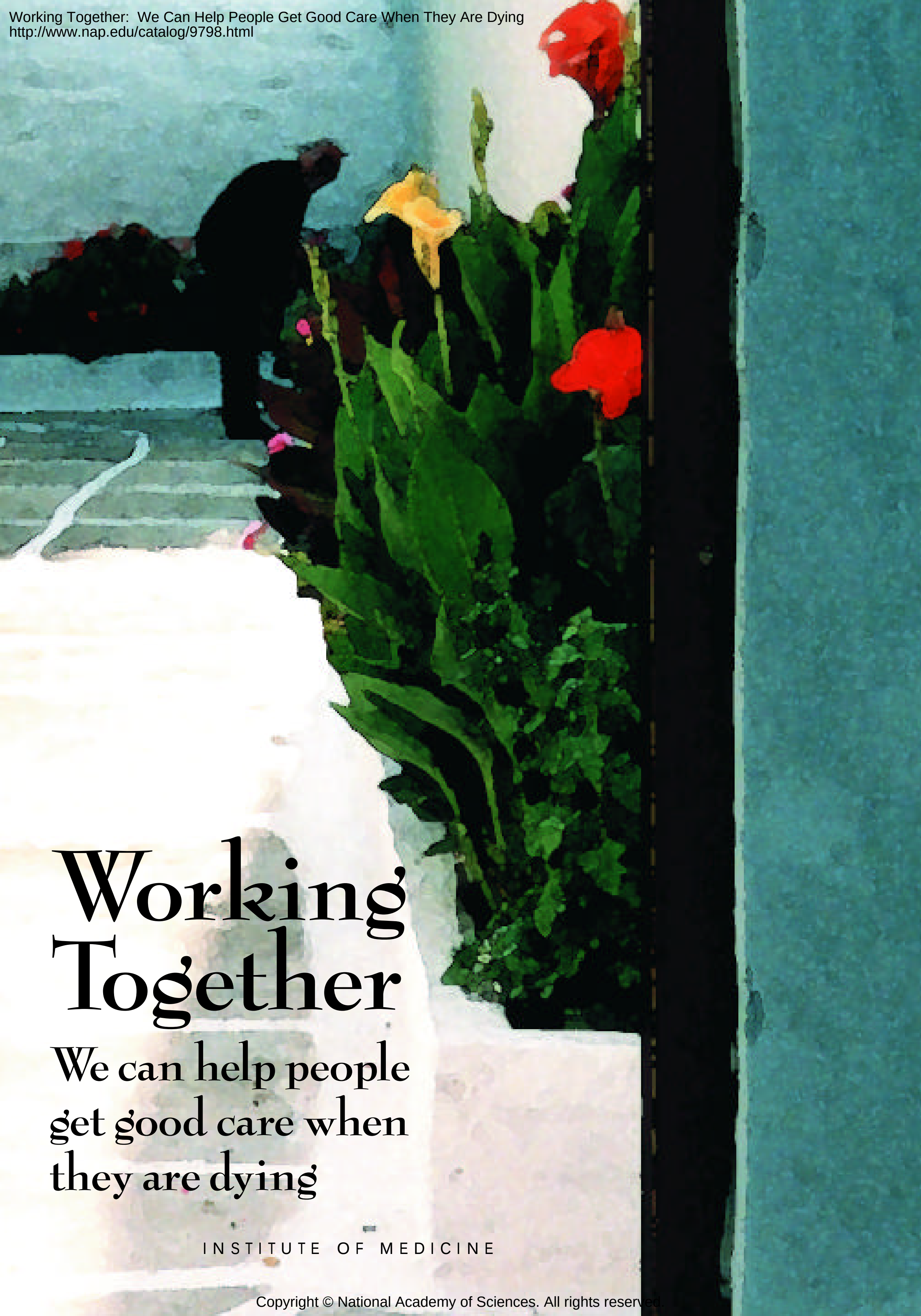


Working Together

We can help people get good care when they are dying

INSTITUTE OF MEDICINE

Dying is both a fact of life and a very deep mystery. Everyone dies, but each person's death is special and different. The way a person dies is very important. No one should have to feel alone, or be in pain, when facing the end of life. People who are dying should not be afraid that those who care for them will ignore their wishes or those of their loved ones.

We need to create a health care system that protects and honors people who are dying. It should help people keep their dignity, even if they have very little control over what their bodies can do.

We know that many dying people do not get good care. But we can change this. We can see that people are not given either too much or too little care when they face the end of life. We can make sure they get pain relief. We can make sure that they are not left alone as they die. We can better train the doctors, nurses, social workers, and others that many dying people and their families depend on.

Change happens when everyone gets involved. Ordinary people need to work with researchers, teachers, health professionals, and those who make the laws. Together, we can make things better for people who are dying and the families who love them.

Studies show:

- Pain and terrible distress do not have to be a part of dying. There are ways to prevent or relieve suffering.
- Patients and families should always be asked what they think is important. What health professionals assume people want or believe may be wrong.
- Dying people and those close to them have many needs. These needs are not only medical. They are also emotional, social, financial, practical, and spiritual.
- Research can help find out the reasons for poor care. It can also help us find better ways to provide good care.

Where we've been
Where we're going

In the United States, one hundred years ago, family members cared for dying people at home. People usually died fairly quickly of diseases like pneumonia. Now, most dying people are cared for in hospitals and nursing homes. And the diseases we die of are often “slow killers” like heart disease, cancer, or Alzheimer’s disease. Today, most adults have not lived with, or cared for, someone who was dying. This can make it difficult for us to think about and plan for good care at the end of life.

We will see many changes in the years to come. Medical care will no doubt get better and better. More people will live into old age than ever before. Caring for the very large group of “baby boomers” as they reach old age will challenge families and the whole society. We need to tackle today the problems that make dying more difficult than it has to be.

What are the problems today?

First and most basic, too many people suffer needlessly at the end of life.

This happens when doctors and other professionals:

- Do not give care that is known to help.
- Do things that are known **not** to work or even cause harm.
- Ignore the wishes and requests of patients and families.

Study after study shows that many dying people suffer needless pain. This is true even though there are many drugs and other ways to relieve most pain. Still, each person's pain is different. Health care professionals cannot decide on their own what is best for a patient. Instead, they must:

- Explain clearly what choices a patient has for pain relief.
- Describe the problems as well as the benefits of each choice.
- Ask the patient what he or she thinks would work best.
- Check with the patient to see whether the approach chosen is helping.
- Work with families, especially when patients cannot make their needs clear.

Second, the education of health care professionals too often ignores the dying patient.

Most caregivers are not trained to:

- Recognize the final phases of illnesses.
- Know what really works in end-of-life care.
- Understand and cope with their own feelings about death.
- Talk—and listen—in ways that help support patients and those who are close to them.

Third, laws, health care systems, and insurance programs sometimes get in the way of good care at the end of life.

Here are some of the problems:

- Outdated laws and ways of thinking can make doctors reluctant to order strong drugs for pain relief.
- Our health care system is complicated. Patients and families often have a hard time finding and keeping the care they need. No one seems to coordinate the patient's overall care.
- Medicare and other insurance programs often do not pay for needed supportive care. Even Medicare hospice benefits—created especially to help dying people—do not pay for many services that help people when they are dying.

Fourth, researchers—and those who pay for research—have not been very interested in studying good care at the end of life.

Most research focuses on curing or preventing diseases and lengthening life. That is very important, but so is knowing about how to help people who are dying. Not enough is known about the last stages of serious diseases. We are finding out more about pain relief, but we still know too little about preventing and treating pain and other symptoms such as nausea, shortness of breath, and fatigue. We also need to find ways to learn whether care meets the needs of dying people and their families.

Is there a "good" way or a "bad" way to die?

When people talk about dying and death, they often have very different ideas about what makes a "good" death or a "bad" death. These ideas are shaped by:

- What has happened to them in life.
- Their culture and spiritual beliefs.
- Their family life—including the death of family members.
- Changes in medical care and the new choices that dying people and their families are often asked to make.

Dying people and their families should be able to expect good care that:

- Helps them be as free of pain and as much at peace with themselves and others as they can be.
- Meets the standards of good medical practice.
- Respects them and honors their values.

"Bad" deaths happen when:

- Dying people suffer pain and other distress that could be relieved.
- Caregivers do not honor the wishes and values of patients and families.
- Those who survive feel they or their loved ones have been badly treated.

Poor care at the end of life sometimes happens because health care professionals are not well trained. But it also comes from problems in the way we organize and pay for health care. And the way we think—or fail to think—about death can block us from tackling these and other problems that lead to bad deaths.

What we can do

We can understand and accept that dying is a part of life. We can learn to value the time of dying. It can be a time for people to grow and for families to come together.

All parts of our society—including health care organizations, governments, churches, and workplaces—can help improve the way people die. Here are five steps we can take:

1. Raise the issue. People should think about, talk about, and learn about the decisions they may face as they or those they love approach death. And people should think about and talk about what they want for themselves or their loved ones at life’s end. Silence is part of the problem within both families and communities.

> For example: The Bill Moyers public television series Before I Die seeks to help people talk about death and dying with family members and in their communities. The shows are available on videotape including one version for discussion groups. A viewer’s guide and suggestions about creating discussion groups are available online at www.wnet.org/archive/bid/p-foroutreach.html.

2. Raise expectations. Dying people and their families should expect good, dependable care. They should expect their beliefs and wishes to be respected. They—we—have to let doctors, hospitals, and government officials, among others, know that this is what we expect.

> For example: The organization Americans for Better Care of the Dying has produced The Handbook for Mortals. The book provides easy-to-read advice for very sick people and their families. It includes advice on how people can talk to health care professionals about what they want and expect. The organization’s Agitator’s Guide: Twelve Steps to

Get Your Community Talking About Dying focuses on community action. One suggestion is to call groups that develop “report cards” on health care organizations. Ask for reports on what these organizations do to help those who are very sick and likely to die. For instance, which local HMOs pay for hospice care? More information is available at www.abcd-caring.org, or phone 202-530-9864.

3. Do what we know helps. Doctors, nurses, social workers, and others need to use what we already know about how to prevent and relieve pain and other symptoms. Educators must help health professionals build the knowledge, skills, and values they need to help their dying patients. Health professionals must understand that it is wrong to believe or say that ”nothing can be done.”

For example:The American Medical Association has a program to teach good end-of-life care to all physicians in the U.S. It will provide CDs and other material to local, state, and national medical organizations and to AMA members. People can encourage their local medical society and health insurance plan to use these resources for group and individual education programs. Patients and family members facing seriously illness can also ask physicians about their training in care for pain, nausea, and similar problems. More information is available at www.ama-assn.org/ethic/epec/epec.htm or the AMA’s Institute for Ethics (312-464-4979).

4. Get rid of the barriers to good care. Doing this will often require support from lawmakers, voters, the media, and health care managers. It will also require knowing more about these barriers. The information resources listed above and at the end of this document can help. Here are some important goals:

- Reform laws, rules, and state medical board policies that make it hard to use opium-based drugs to help people in pain.

- Improve ways of organizing and paying for health and support services so that dying people can find and afford good care—whether at home or in a hospital or nursing home.

- Find better ways to measure when the quality of end-of-life care is good or poor and to learn what actions can improve poor care.

5. Build knowledge. The National Institutes of Health and many other public and private groups should work together to find out more about end-stage disease and end-of-life care. We can use this knowledge to create guidelines for caregivers. Projects to test new ways of organizing and paying for care are important, too.

The time is now!

No one will be untouched by death. The time for open discussion and for change is now. Silence can lead to fear and loneliness when we most need each other. Together, we can create a caring system that people can trust to serve them and their loved ones well at life's end.

Want to learn more? Want to help?

Here are some useful resources for individuals who are facing serious illness or interested in community efforts to improve end-of-life care.

Robert Wood Johnson Foundation Last Acts program (www.lastacts.org) and Open Society Institute Project on Death in America (www.soros.org / death) for more information on community efforts to improve end-of-life care and links to other sites.

Partnership for Caring (www.partnershipforcaring.org) for information on how consumers can increase the demand for excellent care at the end of life.

U.S. Administration of Aging (www.aoa.dhhs.gov / aoa / webres / hospice.htm, or phone 800-677-1116) for links to hospice directories and other resources.

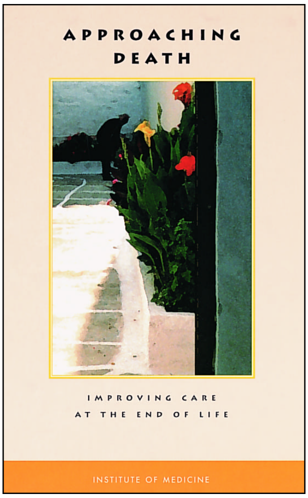
Americans for Better Care of the Dying (www.abcd-caring.org, or phone 202-530-9864) for information about how to deal with serious illness (one's own or another's) and how to promote better financing and delivery of care at the community and national level.

Pain and Policy Studies Group (www.medsch.wisc.edu / painpolicy, or phone 608-263-7662) for information about pain relief and public policy and links to other sites.

To obtain bulk copies (10 or more) of this summary from the Last Acts program at the Robert Wood Johnson Foundation, call 609-951-5753. This summary is also available online on the National Academy Press website (www.nap.edu).

This summary is based on the Institute of Medicine report *Approaching Death: Improving Care at the End of Life*, Marilyn J. Field and Christine K. Cassel, editors. Call 202-334-3313, or visit www.nap.edu to purchase or review a copy of the report.

The report was prepared by a committee of the Institute of Medicine.



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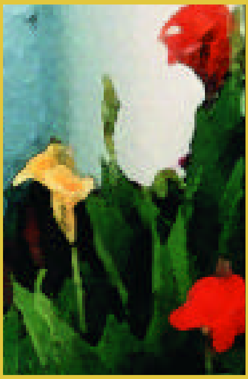

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