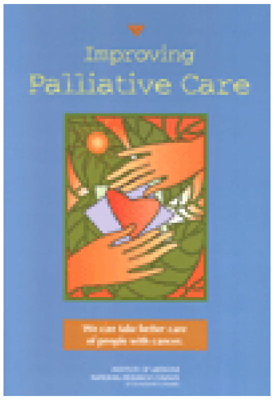

Improving Palliative Care: We Can Take Better Care of People With Cancer

National Research Council

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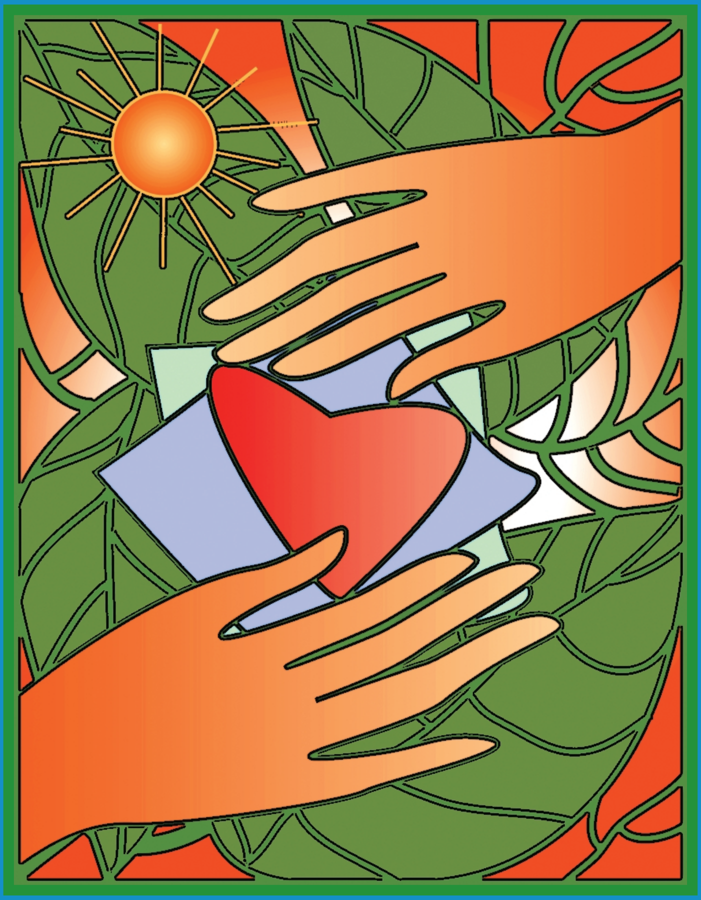
Improving
Palliative Care



We can take better care of people with cancer.

INSTITUTE OF MEDICINE
NATIONAL RESEARCH COUNCIL
OF THE NATIONAL ACADEMIES

"Even the simple things mean a lot. My nurses help me keep as comfortable as I can possibly be."

Nadine, 82

What is palliative care?

Palliative care is the active total care of the body, mind, and spirit. It involves giving support to the entire family. The purpose of palliative care is to prevent or lessen the severity of pain and other symptoms and to achieve the best quality of life for people dying or suffering from a long-term disease. It means treating them as whole persons, not just as people with medical problems. Palliative care acknowledges that people with cancer may need help to:

- Take care of their pain.
- Meet their emotional needs.
- Get the support they and their families may need.
- Work through spiritual issues.

People who have cancer may benefit from palliative care from the time they are told they have cancer, *throughout treatment*, and especially near the end of life.

Palliative Care: Palliative care means making sure a person has what he or she needs to be as comfortable as possible throughout the course of illness. It may mean:

- Giving medicines for pain, anxiety, and constipation.
- Treating tumors with radiation to make it easier to breathe and swallow.
- Helping people get the emotional support they and their families need.

End-of-Life Care: End-of-life care means meeting the needs of people as they near death. When a person is dying, different kinds of needs may become important. For example, the person may need help working through closure with family members or planning for death.

Hospice: Hospice is a program that delivers palliative care to people who are dying and need treatment to prevent or manage pain and other symptoms, even when cure is no longer possible.

We can take better care of people with cancer.

As a society, we have made amazing gains in being able to detect and treat cancer. Even so, about half the people who are told by their doctors that they have cancer will die within a few years. This means that every year about one million people find out that they have cancer and are treated, and about one-half million people die of cancer nationwide.

So far, most cancer research and treatment has focused on trying to cure cancer. There hasn't been much attention paid to other important issues, such as pain control and taking care of other troubling symptoms. Now more and more people are aware that there are cancer care needs beyond just trying to cure it.

Attention is now being paid to helping people with cancer cope better with the problems that may arise when people are being treated or as they approach death.

Palliative care should ensure that people:

- Keep the best quality of life they can have, for as long as they can.
- Have the freedom to choose what treatments they want.
- Get treated to prevent pain and other symptoms, or to control them as best as can be done.

> *"When my doctor first told me I had cancer, I was overwhelmed. There was so much I needed to know. There were so many decisions I had to make. I didn't know how to cope."*
>
> *Shirley, 68*

People with cancer have many symptoms.

Some symptoms are from the cancer itself. Other problems may be caused by treatments they take to fight the cancer. This is true for those who are cured of their cancer and for those who are not. For those who aren't cured, these symptoms usually grow worse in the months and weeks before they die.

People with cancer may:

- Feel pain.
- Have a hard time breathing.
- Feel nausea.
- Feel anxious, worried, or confused.

People with cancer should be able to get care for these and other problems. They and their families should have support to get through the difficult times they may face.

Treating symptoms and lessening the burdens on families allows patients to:

- Keep a sense of control.
- Relieve old conflicts in their lives.
- Strengthen ties with their loved ones.
- Deal with spiritual matters.

> *"Watching my mom's condition deteriorate was hard on all of us. It helped to know that we could help her keep a sense of dignity. We were able to help her do what she needed to do before she died."*
>
> *Susan, 52,*
> *daughter of Joyce, 77*

Why don't people get the care they need?

For many people there are barriers that stand in the way of getting palliative care when they need it.

- Palliative or hospice care is often separated from hospital care. It may not be paid for in the same way as hospital care.
- Health care providers are often not trained in ways to give palliative care or in how to take care of the symptoms of people with cancer.
- Good standards of care for people with cancer, especially those dying of cancer, have not yet been adopted nationwide.
- It may be especially difficult for African-Americans and people from other underserved communities to get the care they need.
- People don't know where to get the information they need about comfort and end-of-life care.
- There is little funding for research to find better ways of relieving the symptoms of cancer and its treatment at the end of life. There is little funding to train health care providers to give that kind of care.

> *"I knew the care my dad was getting wasn't dealing with what he really needed. I didn't know where to go for advice."*
>
> *Tom, 36,*
> *son of Tom, Sr., 65*

Palliative care should not be separated from medical treatment.

Palliative care can improve the lives of people with cancer and their families. It is important to give palliative care along with other medical treatment. At this point, people in the United States can get either medical care to treat their cancer or palliative care, but often not both. Even when people can get comfort care for their symptoms, there may not be much attention paid to their emotional, family, or spiritual needs. Individuals from low-income families or from various ethnic groups are even less likely to get the care they need.

Many people who are dying are able to get hospice services based on palliative care ideals. Hospice patients can benefit from having:

- A team who works together to plan their care.
- A nurse who cares for their medical needs.
- A counselor who supports patients and their families.
- An educator who teaches families what they need to know.
- A chaplain who helps guide them through difficult times.

Hospice patients can also get needed medicines, medical equipment, and supplies.

Hospice services are covered by most private insurance and by Medicaid (in most states) and by Medicare. Because cancer often strikes older people, Medicare usually pays for it. The Medicare hospice benefit covers pain medication and other medicines needed. However, Medicare allows patients to enroll for hospice services only if they are expected to live less than six months. In addition, patients can't get hospice services if they also want to try to fight the cancer to survive. People are often not willing to give up on treatment until they are very close to death.

More than half of all cancer patients who are dying have used some hospice services. But people often wait until the very last days to sign up for hospice services. Some doctors

> *"Getting my aunt the hospice care she needed was such a struggle. It shouldn't have to be like this."*
>
> *Veronica, 25,*
> *niece of Maria, 43*

or families may try to shield patients from the realities they are facing. The strict rules of Medicare also add to the problem. Because of these and other reasons, people who are dying don't get the full benefit of having palliative care in the final months and days of their lives.

And of course, not everyone with cancer has Medicare. For example, parents of children with cancer often have a hard time finding and paying for good hospice care. Many health insurance plans do not pay for some hospice services, like the counseling or other kinds of help families need.

Special needs of children with cancer:

Children with cancer have special needs that must be addressed. They cannot be treated as "small adults." Children with cancer and their families need palliative care, hospice, and end-of-life care. Much of this care consists of frequent counseling sessions so that the child and the family can fully understand the child's condition and what choices are available. Doctors and other caregivers must be able to counsel the parents alone, as well as the child and brothers and sisters. This kind of care should be paid for by health insurance, just like chemotherapy. But more often than not, there is little or no payment for these important discussions.

Research also needs to be done. For example:

- When a child is so ill that he or she may die, parents need information to help them prepare and to help them make good decisions. Research is needed to find out when it would be best to offer this information.
- Children with cancer may have severe pain. Research needs to be done to figure out what treatments work best for children.

> *"At the beginning of Jason's hospice care, his pain was easily controlled by low-dose IV morphine. As the days went on, the pain worsened. When the pain hit, it would take us over an hour of him screaming to get it under control. Knowledge of how to manage pain in children is desperately lacking."*
>
> *Angela, 34,*
> *mother of Jason, 7*

Health care providers need better training in palliative care.

If we want to improve the way we deliver palliative care, we need to improve how we train our care providers. The information we now have about palliative care and its importance is fairly new and needs to be incorporated into training programs. Doctors and other health care providers need to be trained to manage pain and other symptoms. They need to learn how to care for people living with and dying from cancer as well as when and how to refer them to the care they need. The experiences of patients in pain and dying need to be incorporated into medical education. More textbooks and courses need to be developed on the subject of palliative care.

The truth is that most new health care providers leave their training programs with little or no experience in caring for dying patients. In many cases, these new doctors and nurses may have had only a few lectures on the subject. A few schools do have full-length courses on comfort and end-of-life care. Students can decide whether or not they want to attend them, but many do not because it is not required. Most do not get the training and experience they need.

Here is what is needed:

- More health care providers are needed who understand palliative care.
- Textbooks, other written materials, and courses on palliative care need to be developed.
- Training programs need to be coordinated for the many kinds of professionals who care for dying patients.
- Palliative care experts should guide decisions about what doctors need to learn in residency programs.
- Questions about palliative care should be added to licensing and certifying exams.

> *"I was grateful to have had the chance to take course work in palliative care. It has made me much more sensitive to the needs of the dying and their families."*
>
> *Marcus, 32, oncologist*

Standards for palliative care need to be adopted and widely used.

Health care providers, hospitals, and health plans need to plan how they will give palliative care to people with cancer. People with cancer should be able to expect that:

- They will be able to help make decisions about their care.
- Their symptoms will be managed well and their pain will be well controlled.
- They will be able to build trust and rapport with their health care providers.
- They will be satisfied with their care most of the time.
- All the providers giving care will coordinate their services.

> *"We are looking to institute an evaluation system and are beginning to track what people really think about their care. We hope to be able to make important and needed changes in the way we deliver care."*
>
> *Rosana, 44, nurse*

> *"My mother had a painful bone cancer. I couldn't buy her prescribed painkiller at my local drug store. It took me hours on the bus to get what she needed."*
>
> *Bernadette, 45,*
> *daughter of*
> *Wilhelmina, 66*

All people need better access to palliative care.

It is important that all people have access to palliative care. The need is great in many underserved communities, yet palliative care is often not available. For example, African-Americans have a higher rate of certain cancers and of death from cancer than do whites. Yet African-Americans use hospice care less often than other groups. African-Americans and other ethnic communities have a long history of unequal treatment in our health care system. There may be no hospice care available in low-income, inner-city, or rural areas. Many drug stores in these areas do not stock strong pain medications.

There is a huge need for palliative care in ethnic communities. Another issue is that people from various cultures have differing beliefs and traditions regarding care of the dying. Doctors and nurses need to give care that respects these customs. As a society, we need to:

- Train people to give respectful care.
- Research the needs of underserved ethnic groups when it comes to end-of-life care.
- Find ways to make sure all people get the care they need.

People need help in finding out about palliative care and end-of-life care.

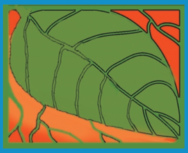
When people find out they have cancer, they often look for information about what caused their cancer, what treatment choices they have and what is going on in research. People can get this information from many places:

- Health professionals
- Family and friends
- Cancer support groups
- Religious leaders
- Printed materials
- Telephone hotlines
- The Internet

Most materials focus on curing cancer and living as a survivor. There needs to be more information provided about palliative and end-of-life care. Booklets and other written materials must describe palliative care and the last stages of cancer, as well as treatment and prevention. These materials must also be written at appropriate reading levels and in the languages that people feel most comfortable reading.

People rely on their health care providers for information about end-of-life care. But everyone, health care providers included, finds it hard to talk about death and dying. Health care providers must be trained and given the experience they need to sensitively talk about end-of-life care—and to *listen* to patients and families, in turn. Both health care providers and families need help in finding acceptable ways to talk about end-of-life care.

> *"I didn't know where to get the information I needed to make good choices for my care. It was really hard to understand what my options were. I really needed it broken down for me."*
>
> *Jesse, 62*



There needs to be more funding for palliative care research and training.

Billions of dollars are spent in understanding why cancer happens and in finding cures and treatments. But little money has been put into research to help take care of the physical and emotional pain—and other symptoms—that people have living with and dying from cancer. This research would greatly benefit people who suffer from cancer. But it would also benefit everyone who has any serious illness or is dying. The cancer research community can lead the way.

The medical community now has new ways to understand the symptoms people experience. For example, now we can take images of the brain. This can help us study pain and depression. We can see how treatment helps. Many more new treatments could be developed. These treatments could give us better control of most of the symptoms people with cancer have. To do this, the government must give the needed funding.

Among many other issues, we need to advocate for more research in:

- How to communicate better with patients who are dying, as well as with their families.
- New ways to control the symptoms of the late stages of cancer and the side effects of cancer treatments.
- How to deal with the emotional, social, and financial issues facing families.

In addition, more dollars need to be spent developing and providing the education and training programs health care providers need in order to give good palliative care to all their patients.

> *"We need to fund more research in palliative care options. We need to make training in palliative care a priority for our health care providers."*
>
> *Joseph, 42, professor*

There is hope.

Palliative care is starting to get the attention it needs. Some new projects are testing innovative ways to give and pay for palliative care all the way through the course of an illness. People are coming up with good ideas that may work very well.

Together we can break down the barriers to getting excellent palliative and end-of-life care to the people who need it. We can find new ways of managing the issues that people with cancer and their families must face. We can make things better for people with cancer today and for those who may face it in the future. We can find better ways to help patients newly diagnosed with cancer, those dealing with treatment and recovery, as well as those coping with end-of-life issues.

After studying the state of palliative care in the United States, the National Cancer Policy Board developed recommendations to improve the system. On the next few pages we summarize their recommendations to doctors, the government, and others who can influence the quality of palliative care.

> *"Palliative care has made such a difference in the day-to-day stuff I have to deal with. It makes things bearable."*
>
> *Fred, 72*

1. Create *Centers of Excellence* in palliative care.

Around our country, the National Cancer Institute (NCI) should name certain cancer centers as *Centers of Excellence* in palliative care. These centers will:

- Give the best palliative care possible.
- Carry out research in palliative care. They could test new and current care guidelines and create new guidelines that may work better.
- Train health care providers in their region.

Here are examples of other things these centers could do:

- Make sure that caregivers in nearby hospitals learn about better ways to treat patients and their symptoms.
- Find ways to make it easier for all people to get palliative care. This may mean setting up outreach programs or training providers in diverse neighborhoods.
- Give fellowships in palliative and end-of-life care for cancer to health care providers and researchers.
- Keep local hospice staff up to date on new ways to give palliative care and to control pain and other symptoms.

"Having a cancer center nearby—where they've made palliative care a priority—has really helped me in my practice. I know I can call them for the latest about treating my patients' symptoms."

Aaron, 49, M.D.

Project ENABLE: **E**ducate, **N**urture, **A**dvise, **B**efore **L**ife **E**nds is a good example of how a *Center of Excellence* might work. The Dartmouth-Hitchcock Medical Center's Project ENABLE team has moved high-quality end-of-life care into three rural communities in New Hampshire. The ENABLE team makes sure patients get proper palliative care throughout their illness. Teaching the patient is a big part of the program. Cancer patients and their families are encouraged to learn how to find the care they need, plan ahead, and keep control of their lives and important choices. The project has shown that "patients need not be abandoned when a cure no longer seems possible."

2. Fund special projects to show how services could and should be given.

The government should fund projects to help develop new ways to pay for and give palliative care.

Each symptom faced by cancer patients needs more research. Here are examples of just a few of the many needed research areas. We need to:

- Find out why so many patients have pain, even though current pain medications are excellent.
- Find more new treatments for pain.
- Test products to improve appetite.
- Find new ways to cope with fatigue.

3. Pay for the true costs of palliative and end-of-life care.

It takes time to work with dying persons and their families. This is especially true of dying children and their parents. There is a need to spend time talking through everything that is going on with the family. Health care team members must talk with each other often. A doctor may get paid about the same for a long, difficult visit like this as for seeing a child with a sore throat. Insurers should make sure they pay fairly for this special type of care and the time it takes to provide it.

> *"We're working to get new legislation in our state to make it possible for insurance to cover palliative care. I know it's going to help make a big improvement in the kind of care families get."*
>
> *Rebecca, 42, activist*

"The health care educator walked me through my choices and explained everything really well. It was important to me that my family knew what to expect."

Hana, 62

4. Give people the information they need about palliative and end-of-life care.

Health care providers and groups providing information about cancer prevention and treatment should also provide information about palliative and end-of-life care. People should have information about palliative care all through the course of their disease. People also need to know what to expect at the end of life.

All written materials should:

- Be written in plain language so they can be easily understood.
- Meet the needs and values of the people who will read them.

Booklets and other kinds of written materials should be made especially for:

- Children with cancer and their families.
- People of different ethnic backgrounds and beliefs.

Other ways of getting information to people, such as videos, awareness campaigns, or television programs need to be created.

5. Create standards of care to help health care providers deal with pain and the other problems people with cancer face.

The health care profession is responsible for creating standards of care that spell out what good palliative care means. Professional societies that represent doctors, nurses, and social workers in cancer care should work together to create, test, and use the best possible practices in the care they provide to people with cancer throughout their treatment and at the end of life.

6. Make sure that palliative care and end-of-life care improves.

We need to:

- Develop a standard way to measure the quality of palliative care and end-of-life care.
- Support research and projects that show how to give excellent palliative and end-of-life care.

We can make a difference!

Cancer is something that affects us all. We shouldn't let another day pass in which cancer patients suffer needlessly. The tragedy is that we know how to provide palliative care and relieve much of the pain people endure. Now is the time for change. All of us must work together. Our doctors and nurses, our insurers, and our government officials need to work together to give cancer patients the best care possible. We must all advocate for good palliative care.

Each of us can work to make a difference. Together, we can create a caring, respectful healthcare system that people can trust to serve them and their loved ones as they go through the crisis of cancer.

> *"My family was brought closer together through this crisis. The loving, respectful care we got really made a difference to all of us."*
>
> *Chris, 53*

About this booklet and the National Cancer Policy Board:

This booklet is based on a report called *Improving Palliative Care for Cancer* put out by the National Cancer Policy Board (NCPB). The board is made up of medical professionals who are national experts in the treatment of cancer and in cancer research, as well as individuals representing the public. The NCPB is a joint effort of the Institute of Medicine and the National Research Council of the National Academies.

When the Board began to study palliative care, it asked for input from experts all around the United States. These experts wrote chapters on subjects ranging from the costs of palliative care, to the way doctors, nurses, and social workers learn about palliative care when they are in training. The chapters described the current state of the art in palliative care and identified opportunities for improvement. The NCPB used this information to identify problems, chances to do better, and the steps that the government and others could take to improve palliative care for people with cancer.

This booklet shares with the public what the NCPB learned about the state of the art in palliative care and what it recommended to the policymakers. The premise of the booklet is that the more everyone understands about the problems and possible solutions, the more effective we can all be in making the health care system better for people with cancer and the families who love them.

To purchase or review a copy of the original report, *Improving Palliative Care for Cancer*, visit the National Academies Press website at www.nap.edu. This booklet is also available at that website.

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We can make a difference.

We can make sure that people with cancer get the help and support they need to:

- **Take care of pain and other symptoms.**
- **Meet their emotional needs.**
- **Work through spiritual and physical distress.**
- **Keep the best quality of life they can have for as long as they can.**
- **Strengthen ties with their loved ones.**

This is what palliative care is all about. We can improve palliative care for people with cancer. We can work together to help people get the care they need.

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