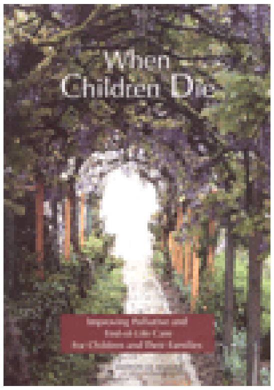

When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families--Summary

Marilyn J. Field and Richard E. Behrman, Editors, Committee on Palliative and End of Life Care for Children and Their Families

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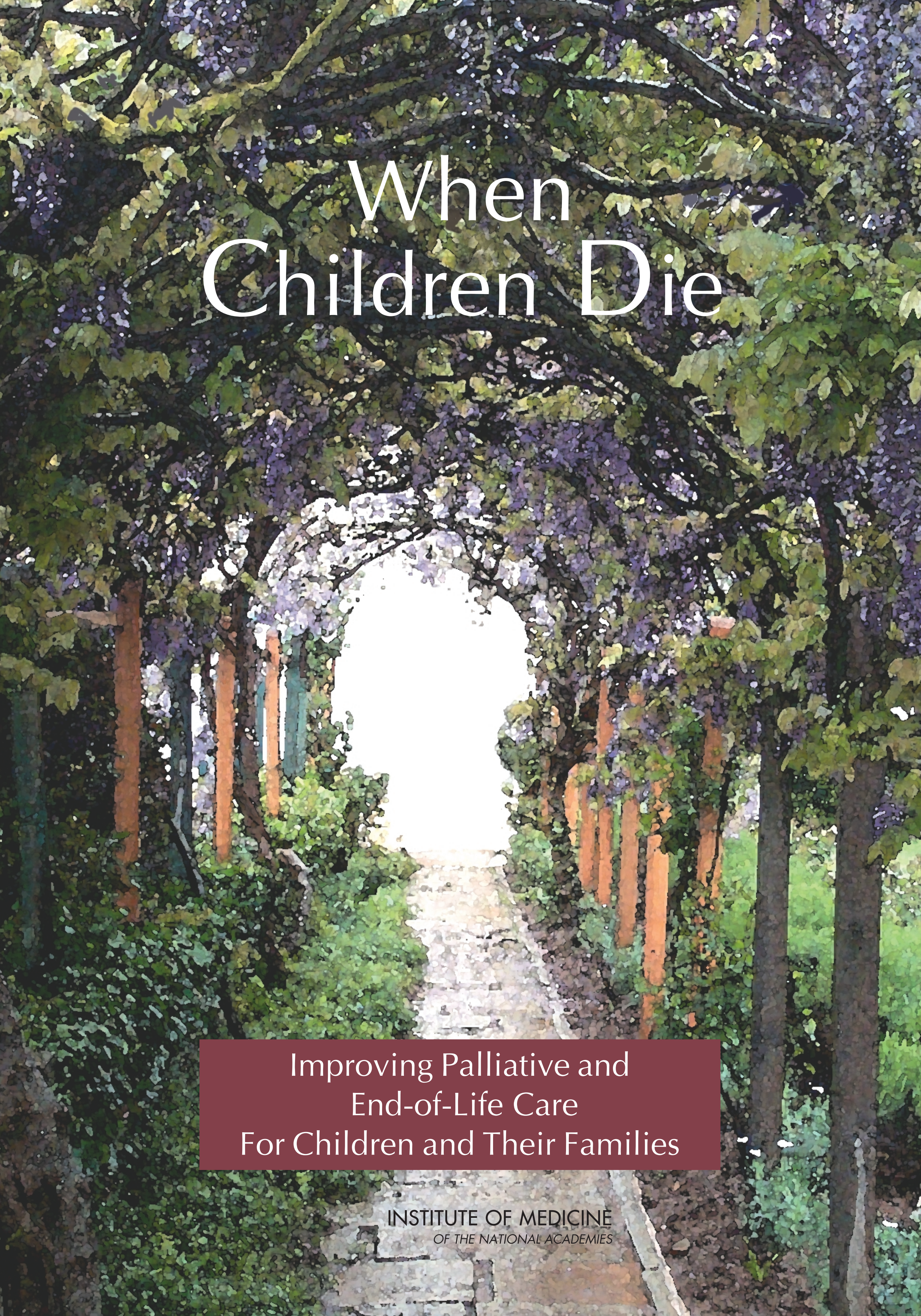

When Children Die

Improving Palliative and End-of-Life Care For Children and Their Families

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

This document is a brief summary of
the Institute of Medicine report entitled
*When Children Die: Improving Palliative and
End-of-Life Care for Children.*

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How do children with a life-threatening illness or injury cope with that reality? How do families deal with such a devastating blow? Children, parents, siblings, and grandparents face difficult and overwhelming questions:

Am I going to be OK? Will our child survive? Why is this happening to my grandchild? If it can happen to my brother, will it happen to me too? Is it going to get worse? How can we get help for our child's pain? Are we doing everything we can? Why is my sister at the hospital so long? What kind of care would be best? How will we make it financially? How can we deal with all the details? Who can help us get through this?

In such difficult times, children and their families need "medicine with a heart." They need what palliative care has to offer from the moment they learn a child is very ill.

What doctors, nurses, and other health professionals do and say makes a real difference. They can ease children's pain and other symptoms. They can offer words of comfort and give children and families the information they need to understand what is going on. They can help families make choices and support them in dealing with sadness, fear, worry, and loss.

Others can help too. Insurance companies and government agencies can make it easier for children to get palliative and end-of-life care. Those who educate health care professionals can train them to better provide this care. Researchers can find out what works best to help very ill children and their families.

We need medicine with a heart. . . The endless physical, emotional, and financial burdens that your family carries when a child is dying. . . make you totally incapable of dealing with incompetence and insensitivity.

Salvador Avila, parent

Michael's doctor worked the entire way knowing that if Michael didn't make it, we were still going to have to get through it. So she treated us, as well as treated Michael.

Rose Conlon, parent

What is palliative care?

Palliative care supports and comforts children with life-threatening illnesses or injuries. Its purpose is to:

- Prevent or relieve pain and other physical distress.
- Offer children and families – especially parents, brothers, sisters, and grandparents – the emotional and spiritual support they need.
- Help children and families live as normal a life as they can.
- Help families make decisions.
- Give them timely and truthful information.
- Respect families' choices, values, and cultural traditions.

Palliative care works *with* – not *instead* of – other treatments. It can start as soon as the family knows the child is ill. Palliative care does not mean "giving up." Good palliative care can help all seriously ill or injured children, not only those who are dying.

End-of-life care and ***hospice care*** focus on taking care of children as they near death. They can help each family:

- Ease their child's pain and other symptoms.
- Keep their child calm and comfortable.
- Make decisions about the use of life-support.
- Talk about last wishes.
- Grieve the death of the child.

When children need palliative care.

Children and families need palliative care beginning when they learn of the serious medical condition. They need it all through treatment and at the end of life. The care that children need will change as their condition changes. And at each stage of life – infant, child, and teen – children's needs will differ.

Why it can be hard to get palliative care.

Too often, children who are very ill or dying do not get the kind of care that meets their needs – both physical and emotional. This happens for many reasons:

- Health care professionals may not have the training they need to give palliative care. And because they are not familiar with it, they may not be able to explain to families how palliative care can help.
- It can be hard for both doctors and families to talk about death, even if death is very near.
- Sometimes families are forced to choose between treatments aimed at cure and palliative care.
- Children's needs can be very complex. Parents may need a lot of help coordinating a child's overall care. Often a family must travel far from home to get the kind of care the child needs.
- Health plans may not cover palliative or hospice care. And many children have no health plan at all.
- There has not been enough research to find out what really helps children and their families.

Also, if families are new to this country or have different cultural traditions and values, they may have added problems getting palliative care. They may not speak the same language as their care providers. They may look at illness, medical treatment, and death in a different way.

> *Was there someone in charge of my child's medical care? Yes, me. Coordinating the various doctors, nurses, and treatments was the most frustrating part of the process.*
>
> ***Christine Aney, parent***

We can give very ill children the palliative care they need.

Children need special care when they are seriously ill or injured and when they are dying. To make this happen, the way children get care must change.

This booklet highlights ways we can improve palliative and end-of-life care for all children and families who need it.

These ideas for change reflect four basic challenges:

1. **Children should have care that is focused on their special needs and the needs of their families.**
2. **Health plans should make it easier for children and families to get palliative care.**
3. **Health care professionals should be trained to give palliative care to children.**
4. **Researchers should find out more about what care works best for children.**

The good news... is that any health care organization in the country can take immediate steps to improve how it cares for dying patients and those who love them.

Joanne Lynn, MD

1. Children should have care that is focused on their needs and the needs of their families.

Each child and family is unique. Good palliative care respects each family's personal needs and cultural values.

Palliative and end-of-life care makes sure that each child's needs are met – body, mind, and spirit. Such care helps families to:

- Find and coordinate the care their child needs.
- Keep day-to-day life as normal as they can.
- Prepare for the future.
- Give a child's brothers and sisters the support they need.

Here are a few suggestions to help ensure that children and their families get excellent care.

Provide good information and help families with choices.

Families need to understand what they face and what their choices are. Palliative care professionals know how to help families:

- Get complete and easy-to-understand information about the child's condition, both present and future.
- Talk about the choices for treatment, including palliative care.
- Understand the pros and cons of each option.
- Think through each choice in the light of their needs and values before making their decisions.

> *It was terribly important for us to do exactly what was right and necessary to help our daughter. . . Our nurse and social worker made us feel that we were, in fact, doing everything in our power to take care of our daughter.*
>
> ***Kathleen and James Bula, parents***

The ones who tell me are my friends.

Benjamin, child with cancer

Talk with children.

Good care respects both the child and the family. Children, especially teens, can handle more information than adults often think. They should be given the opportunity to:

- Find out about their medical condition.
- Learn what the future might hold.
- Talk about their feelings and worries honestly.
- Hear about what choices for care they have.
- Help decide about their medical care when they can.

Parents, health care professionals, social workers, and other experts should work together to create guidelines on how best to involve children. These guidelines should:

- Take into account how children think, feel, and talk.
- Consider children's needs at different ages.
- Respect children's wishes.
- Honor families' values, cultures, and traditions.

Strengthen team care for children and their families.

The palliative care team includes doctors, nurses, social workers, chaplains, and others who know how to care for children. Where teams like this exist, they work closely together and with families to plan, provide, or arrange for all needed care. This is important because children often need care from different organizations and in different places – doctor's offices, hospitals, hospices, clinics, at home.

Coordinating all these services can put untold stress on families. Care providers should work with family advocacy groups to create and follow guidelines that will make getting care – whatever or wherever needed – as easy as it can be.

Create regional resource centers for palliative care.

Children who are very ill or injured often go to special medical centers for treatment. When they return home to small towns, or rural areas, families may have few resources. Local doctors and hospitals may not be expert in pain and symptom management and other aspects of palliative care.

Regional resource centers can offer help in person, by phone, or by email. These centers can:

- Give advice to a child's doctor or family.
- Offer training to health care professionals.
- Provide families and health care professionals with written guidelines and care plans.

Her words concerning his death and the choices I made also comfort me. She said, "You did the right thing." Such simple words—but what comfort they give me four years later!

Peg Rousar-Thompson, parent

Support each family after a child dies.

A child's death is a terrible loss. Not only does the immediate family grieve, but the loss affects the extended family, schoolmates, friends and neighbors, and others in the community.

Most grieving families get their strongest support from their personal circle of family, friends, and spiritual advisors. Still, families should be informed about outside resources:

- Bereavement services of the hospital or hospice.
- Community support groups for grieving parents, siblings, and grandparents.
- School counselors and special camps for brothers and sisters.
- Mental health professionals, especially grief counselors.

The doctors, nurses, social workers, and others who cared for the child can also comfort grieving families. These professionals must develop the skills to do this well. In addition, health care providers should work with bereavement and family support groups on guidelines to help grieving families.

We had such frustrations with insurance. You need to have a business degree, I think, to deal with these things.

Winona Kittiko, parent

2. Health plans should make it easier for children and families to get palliative care.

We need to change the way palliative care is paid for. Most private health plans and Medicaid plans cover hospice care for children. But such care is often limited to patients who are expected to live less than six months. Also, families may have to agree to stop any treatments meant to cure their child. Such choices are terribly hard. Parents want to give their child every chance to survive.

All health plans – public and private – should cover palliative care for children. All plans should drop any rules that require a child to stop other medical treatments in order to get palliative or hospice care.

Palliative care means more than giving comfort when a child is near death. Health plans and insurance companies need to cover the full range of palliative care services. From the time the child first becomes seriously ill, the health care plan should pay for the time needed by doctors and other team members to:

- Talk to and counsel the child, their parents, as well as brothers and sisters.
- Consult with experts in palliative care when needed.
- Give support to family members after the child's death.

Public and private health plans, health care professionals, and family advocacy groups should work together to support these changes. They need to set standards for covering palliative care.

3. Health care professionals should be trained to give palliative care to children.

Professionals should be trained how best to provide palliative and end-of-life care. If they are not, they may not do enough to prevent pain and other symptoms. And they may not be prepared to talk to families about death and dying and about important choices. They should not have to learn all this by "trial and error" as too often happens today.

Medical, nursing, and other health care schools or programs should:

- Prepare all health care professionals who will work with children and families with basic skills in palliative care.
- Prepare those who will most often care for very ill or dying children with advanced skills in palliative and end-of-life care.
- Prepare palliative care experts to act as role models, to train others, and to do research on palliative care for children.

> *I have had parents and patients tell me, years later, about the searing impact of poorly delivered bad medical news. But I have also had them tell me about compassionate, tender physicians who did it well. . . I knew there should be training in how to do this better.*
>
> ***Joanne Hilden, MD***

The time that he was sick was so confusing. . . I hated to see my brother in pain. . . Sometimes I got mad at my parents. I couldn't communicate with anybody. Really, it was because I felt a little neglected when he was in the hospital. It was lonely.

Susan Rae,
sister

4. Researchers should find out more about what care works best.

More and better research is needed to improve palliative care for children and the whole family – parents, brothers, sisters, grandparents. We need to know more about what care works and what does not.

Right now, funding for palliative care research in general is small. Funding for research on children's palliative care is even smaller. So, health care professionals and families must often make decisions about the care of children with little guidance.

The National Institutes of Health and other public and private groups should increase support for research on palliative care for children and their families. Research should cover each stage in a child's growth – infant, child, and teen. It should cover care from the time families hear about the illness through treatment, death, and bereavement.

For example, research is needed to find:

- What treatments work best to ease pain and other symptoms.
- How better to talk with the family, including an ill child's brothers and sisters.
- New ways to deliver, coordinate, and evaluate care.
- Better ways to help the family after a child's death.

We can improve palliative care for very ill children and their families.

This booklet has talked about ways we can improve care for very ill children and their families. We can:

- Give families good information and help with making choices.
- Let children talk and ask questions about their concerns.
- Strengthen team care to serve children and their families.
- Create regional resource centers for palliative care.
- Support each family after a child dies.

Other ways we can change things for the better are to:

- Change health plan policies that make it hard for children and families to get palliative or end-of-life care, and for medical teams to provide it.
- Help health care professionals improve their skills in palliative care.
- Do research that will fill gaps in what we know about good palliative care of children and their families.

The life-threatening illness or death of a child is overwhelming and hard to face. But we can do more to ease children's pain and suffering and to support their families.

If health care professionals, policymakers, insurers, and family advocates work together, we can change the kind of care very ill or dying children receive. We can help create a care system that all children and families can rely on and trust.

The goal of palliative care is "to add life to the child's years, not simply years to the child's life."

American Academy of Pediatrics

When you first get sick, you have to live.

Katherine, 19-year-old with cancer

A word to families . . .

If you have a seriously ill child, find out more from your child's health care team about palliative care and how it might help your child and the whole family.

- Ask for clear information about your child's medical condition. Be sure that all your questions are answered.
- If you are confused or if you can't understand what is being said, tell your care providers. Ask them to repeat what they've said. Ask them to find another way to explain it.
- Ask what will be done to keep your child comfortable. Make it clear that this is very important to you.
- Learn about all the treatment options and the pros and cons of each.
- Find someone you and your child can talk to about what you are going through. Don't hesitate to ask for the support you need.

As you hope for the best, asking these questions and getting the answers you need will help you prepare for whatever may lie ahead. You will then be able to focus more on what matters the most – caring for your child and making the most of your time together.

This summary is based on the Institute of Medicine report *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*, Marilyn J. Field and Richard E. Behrman, Editors. The report was prepared by a committee consisting of:

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We can improve palliative care for very ill children and their families.

The life-threatening illness or death of a child is overwhelming and hard to face. This booklet outlines ways health care professionals, policy makers, insurers, and family advocates can work together to improve the kind of care very ill or dying children receive.

We can help create a care system that all children and families can rely on and trust. We can:

- Help prevent or relieve pain and suffering.
- Provide children and families with the information they need.
- Give them emotional support.
- Respect families' choices and values.
- Help families make difficult decisions.

These are some of the ways palliative care supports and comforts children and their families.

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