

# Life's Toughest Moments

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*A Parent's Guide When Facing End of Life  
Decisions With Their Child*

*Authors: Jennifer Smith, RN and Bradie Kvinsland, CCLS*

*Authors of "One Step at a Time"*

Encourage  
Comfort

HOPE  
Trust  
Inspiration

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Life Decisions With Their Child*

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A Global-HELP Publication

Encourage  
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Love  
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Inspiration

## DISCLAIMER

This book should not be used as an alternative for professional care. It is meant to be used for documenting care, exploring feelings, and informing parents of the routines of hospitals in a general sense. There is no guarantee that the information in this book will remain current over time. The appropriate professionals should be consulted with respect to the care of the hospitalized patient and those involved in their care.

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# About This Book

*Gaining a sense of control*

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*Life's Toughest Moments* will provide you with a sense of control. This period of time may seem as if you are walking through a thick fog... with no sense of direction.

Your child's doctors may have told you that the medical treatments are not going to save your child's life. Your health care team will begin asking you questions about how you and your family would like to influence this precious time with your child as curative care changes to supportive care. The hospital has systems in place to answer your questions, discuss options and give support to your whole family.

If your child is not getting better, you may want to begin thinking about you and your child's wishes regarding their end of life. If you are focused on extending your child's life with machines and second opinions, you may not be fully present with your child at the moment of his or her death.

*Life's Toughest Moments* provides:

- ◆ Definitions of medical words
- ◆ Answers to difficult questions
- ◆ Exploration pages
- ◆ Ideas to create memories with your child and family
- ◆ Caring for surviving children
- ◆ Quotes and tips from parents who have had a child die
- ◆ Ways to cope when your child has died
- ◆ Ways to talk to your child about death
- ◆ Tips on healing

Love of  
HOPE  
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Comfort  
Trust  
Ties

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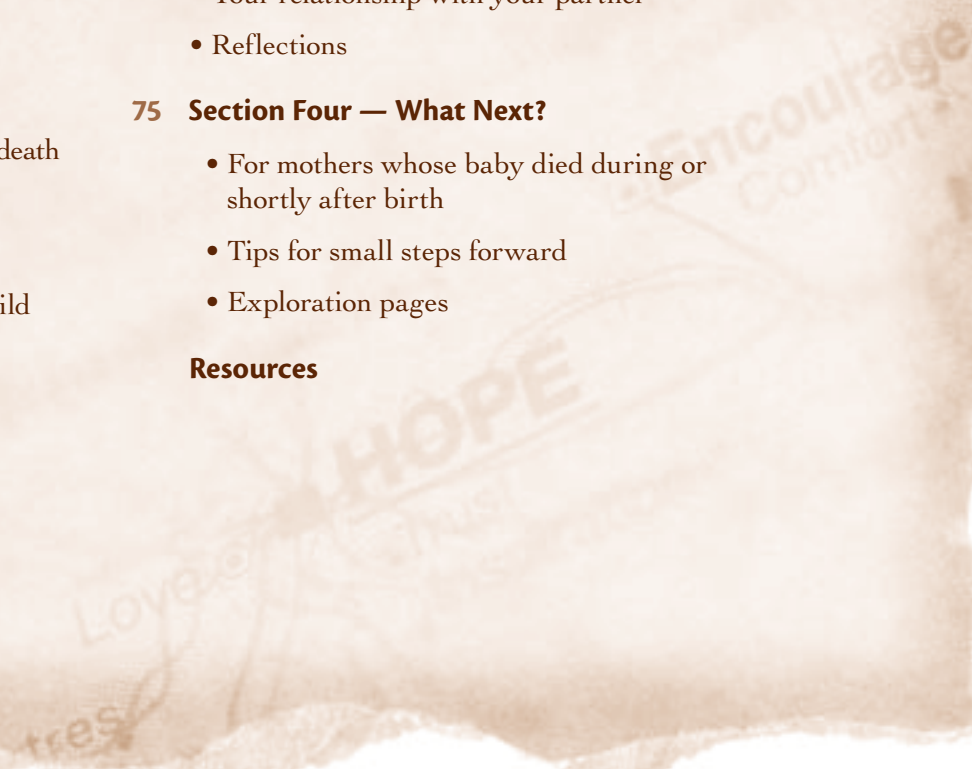
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## **Resources**



Some of this may be difficult to read. If you are not ready, turn that page and go to others. There may be information that you have had questions about but have had trouble putting into words or were afraid to ask. This book offers coping tips as well as questions to ask yourself and your hospital staff. It also includes simple but important ways to create memories of your child's life.

You may be a parent who has lost a new baby, a small child or a teenager. Some information may not apply to your exact situation, but keep reading. You will find many topics and interviews from parents who have had a child die—from a new baby up to 16 years of age. The authors have chosen to use "child" to be all-inclusive of neonates, term infants and older toddlers up through teenage children.

Providing the best medical care often means intervention with medicines, machines and operations. It can also mean focusing on the comfort of your child. By ensuring that your child's last few days are comfortable, you are advocating for your child. This is a large accomplishment and something to be proud of.

Hospital Language

Support

Difficult Questions

Answers to Difficult Questions

1

Encourage  
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## What do all of the medical words mean?

### What is a care conference?

A care conference is a meeting where you and your child's health team discuss treatment options and plans. The health care team may include doctors, nurses, your social worker and anyone else that has helped care for your child. The role of your child's health care team is to provide you with information to understand and discuss the next steps. There may be several options to consider. You and your family may make decisions at a later time or express your wishes during the meeting. Once you have had time to talk and think, create a written plan that will serve as a guide for your health care team. Please see the Decision-Making Tool at the end of this section to use as a guide during your care conference.

### What does "code status" or "DNR status" mean?

"DNR" stands for "Do Not Resuscitate." Your health professionals need to know how far to carry out life-sustaining treatments for your child. If you and your family would like medical support to continue your child's life, you will hear people say that your child is a "full code," meaning that everything possible will be done to keep your child alive.

When it is clear that your child will not get better, you and your family may decide to change to supportive care. At this time you will hear your team referring to your child's code status as "no code" or "modified DNR." "No code" means that your health care team will not start additional therapies. A "modified DNR" means that there will be some additional therapies such as oxygen or medicines but that the therapies are limited based on your family's wishes.

### What power do I have as a parent in making decisions about my child's code status?

The health care team involves you, as parents. Your wishes will be discussed with your doctors and nurses. Together, you will come up with a plan that includes your ideas, your child's desires and what is actually possible with the health care team.

**Tip:** It is a good idea to write down your questions and bring them with you to a care conference.

You may also want to take notes during the meeting to refer to later.

## Medical Words

### **What is CPR?**

CPR stands for Cardio-Pulmonary Resuscitation. CPR is done when a person stops breathing and her hearts stops. The health care team performs chest compressions (pushing on the chest) in a rhythmic motion to help the heart circulate blood to the brain. An “ambu bag” helps to put oxygen in the lungs with a bag and a mask, instead of mouth-to-mouth breathing that the public is taught to be used when a person collapses and stops breathing in public.

There may be a mistaken belief about CPR and the positive benefits it has for children. If a child’s heart stops working, it is usually one of the last organs to become sick. Children’s hearts are normally strong. If a child has to be revived by CPR, the chance for survival is slim because the other organs are so sick. In an adult, CPR is often much more helpful because, once the heart is revived, every other organ is more likely to be working well.

Your health care team may have talked with you about your child’s health status clearly not improving. They may have been, in essence, attempting to revive your child for hours, days, maybe even weeks or months. Although the process of trying to cure your child has gradually led to more and more treatments, CPR is the last possible option. There comes a time when curative treatment

must shift to comfort treatment.

### **What is an Ethics Committee for?**

Sometimes the health care team does not agree on common treatment plans or they do not agree with your family’s decisions. In other cases your family may not agree with how the health care team is handling your child’s illness. In these cases your child’s care will be discussed with the hospital’s Ethics Committee. This committee will help guide your child’s care from an outsider’s point of view. An Ethics Committee is only advisory. It is made up of a wide range of skilled people such as doctors, nurses, attorneys, psychologists and social workers. This helps bridge communication between everyone involved in your child’s care.

### **What is the Palliative Care Service?**

This is a team within the hospital made up of social workers, nurses, chaplains and doctors who are able to talk with you about difficult decisions. Palliative Care should not be confused with end-of-life care as it is a comfort-based approach to caring for your child. They can help express your needs and feelings to the health care team and help manage care if there are many people involved with your child. Take a moment to ask within your hospital how Palliative Care can best help you and your family.

## Medical Words

### What does it mean to “withdraw support”?

This is a term that is being used less often, but refers to medical treatments that have helped keep your child alive, that are then taken away. Withdrawing support, or allowing for a natural death, is different for every child and every family. Ask your team what this would mean for your child. Your health care team will begin talking with your family about allowing for a natural death when it is clear to them that your child’s body cannot recover with medical treatment.

### What does “extubate” mean?

The removal of a breathing tube that helps a person to breathe.

### When they say they are going to “take out lines,” what does this mean for my child?

Sometimes it is possible to remove IV’s so that your child is not connected to as many tubings. Many times the IV’s are serving a purpose such as delivering medicine, allowing for constant blood pressure support, allowing for therapies such as constant dialysis or oxygenation of blood. When these lines are removed, it may speed up your child’s death.

### What other questions do you have for your health care team?

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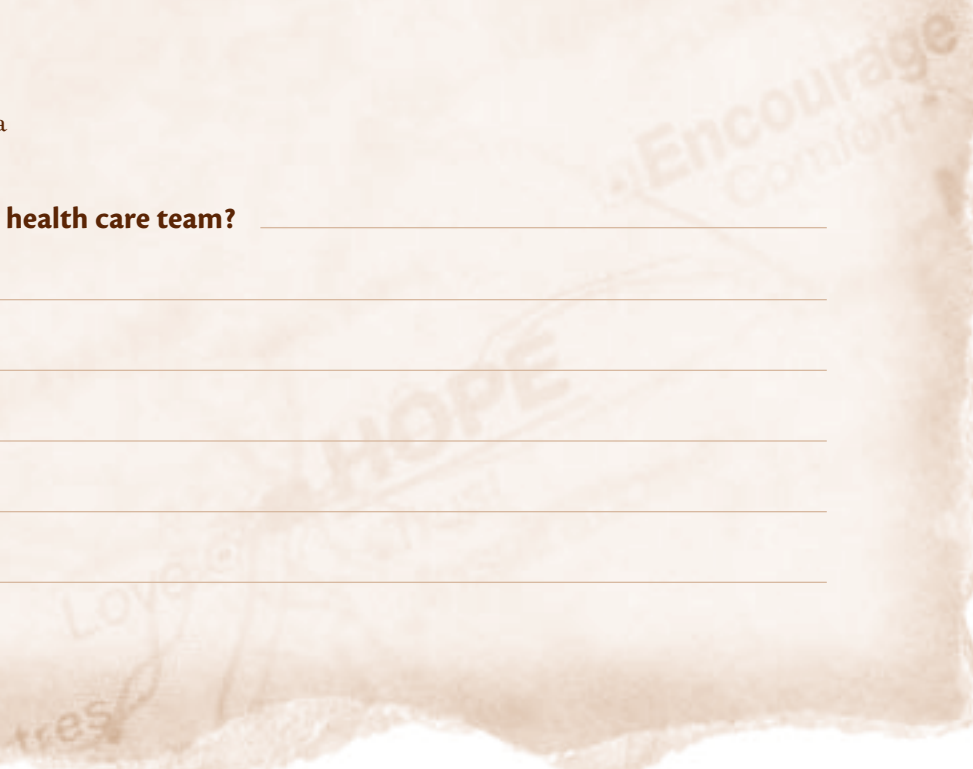
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**What rights do I have under the Family Medical Leave Act?**

Covered employers must grant an eligible employee up to a total of 12 work weeks of unpaid leave during any 12-month period for one or more of the following reasons:

- For the birth and care of the newborn child of the employee;
- For placement with the employee of a son or daughter for adoption or foster care;
- To care for an immediate family member (spouse, child, or parent) with a serious health condition or
- To take medical leave when the employee is unable to work because of a serious health condition.

**Tip:** Find out what options your workplace has for you. If your employer has a Human Resources/Benefits department, check with them to find out what is available through FMLA and /or employer benefits. If your employer does not have this department, check with your supervisor or manager.

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## About An Autopsy

### Who performs an autopsy?

The doctor who performs an autopsy is called a pathologist. The pathologist accepts your child's body as his patient and he performs the procedure carefully and respectfully in an operating room environment.

You may indicate restrictions in the autopsy that make you more comfortable, but doing this may restrict the amount of knowledge that can be obtained.

### Will I know the autopsy results?

It is very common for autopsy results to be shared with you. You may speak with your doctor about a plan to review the results, whenever you are ready.

### When will I know the autopsy results?

Usually a final written report is available within several weeks to months, or possibly longer if special studies are required.

### If I elected to not have an autopsy performed, can I change my mind?

If you have initially decided against an autopsy but change your mind, it may still be possible to ask for an autopsy in order to gain valuable information after your child's funeral.

### Does an autopsy cost money?

Most hospitals cover the cost of an autopsy but some do not. Find out what your hospital covers, as medical insurance companies do not reimburse you for the procedure.

### Do autopsies leave visible marks?

Some families are concerned that a viewing will not be possible after an autopsy is performed. Your child's pathologist will make incisions in locations that will not be visible once your child is dressed. Your child's hands and face are not affected. Feel free to ask questions and make your desires known to your doctors prior to the autopsy.

# About An Autopsy

## Is an autopsy necessary?

Many parents do not wish to think of their child's body having an autopsy. That is all right. Some feel that an autopsy is pointless as their child's life has been taken away and nothing can be done to change that. However, an autopsy can be of benefit to you, your family and your health care team.

## What are possible reasons to have an autopsy?

An autopsy often gives more information about the cause of death than had been known before. Receiving more facts may help to obtain some closure with your child's death. The procedure may find a genetic trait that could be invaluable information for your other children or future children. On the other hand, if your family has been told that your child has a genetic disorder that led to a death, an autopsy could disprove this, thus lifting the concern. From a medical standpoint, more can be learned from the disease in order to help other children and families.

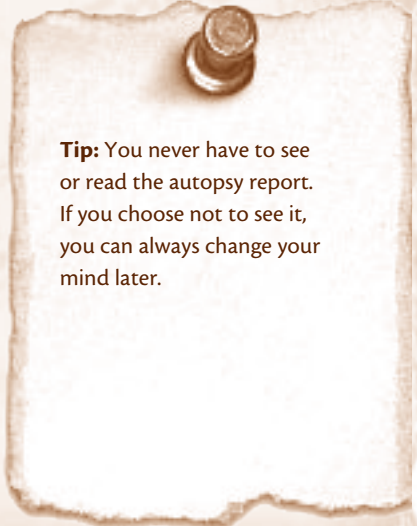
## When is an autopsy required?

Any death that is sudden, unexpected, unnatural, suspicious or violent must, by law, be reviewed by a medical examiner or coroner. A medical

examiner is an appointed forensic pathologist who performs her work with care and respect. The autopsy performed by the medical examiner is the same procedure as that is followed with the hospital's pathologist. Sometimes the medical examiner is called a coroner, who is an elected official who investigates deaths. When an autopsy is required, the medical examiner contracts with local pathologists. If you have cultural or religious beliefs that go against an autopsy, discuss these with your doctors to see if other options are possible.

## Is there any reason organs cannot be donated?

Generally, the only instances where the medical examiner will prevent organ donation are in death as a result of murder, especially of infants or children where there may be hidden injury.



**Tip:** You never have to see or read the autopsy report. If you choose not to see it, you can always change your mind later.

8 **Bring these questions to your doctor when autopsy is discussed**

**How long will the autopsy take?** \_\_\_\_\_

\_\_\_\_\_

**How will I know when I can schedule funeral services?** \_\_\_\_\_

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**How will I know if we can have an open casket?** \_\_\_\_\_

\_\_\_\_\_

**Where is the autopsy going to take place? In the hospital? At the medical examiner's?** \_\_\_\_\_

\_\_\_\_\_

**Can I meet with the pathologist who will be doing the autopsy?** \_\_\_\_\_

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**May I have someone else present when the autopsy is being performed?** \_\_\_\_\_

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**How do I contact the pathology department if I have questions after I leave the hospital?** \_\_\_\_\_

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**Who will give me the results of the autopsy once it is completed?** \_\_\_\_\_

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**When will I get the results of the autopsy?** \_\_\_\_\_

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**If I make limitations in the autopsy, what information will I not receive as a result of my requests?**

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**What information may be gained by allowing for an autopsy?**

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## Organ Donation

### **Here are some facts about donation that may be helpful as you make decisions about organ donation:**

- Most major religions acknowledge that donation is a good-samaritan act of giving life.
- Organ and tissue recovery happens only after every effort has been made to save the life of your child.
- Your child will be treated with care and respect during the donation process. The donation of organs and tissues does not eliminate the option of an open casket funeral.
- Funeral arrangements are usually not delayed because of donation.
- There are no costs to your family associated with organ donation.
- You may receive general facts about the recipients if you wish. Sometimes sharing families would like to get in touch with each other. You can request confidentiality or direct communication. This is organized through your local organ donation group.
- If you choose, your family will be able to remain anonymous.

### **Will I be approached to donate my child's organs?**

It is important to know that some deaths occur without the potential for families to be approached for organ donation. Doctors or nurses trained by your local organ donor program may speak with you if your child has the potential to donate. The organ donor professional uses the utmost care to allow your family to make an educated decision about donation. Judgment is not placed on your family if you decide not to donate. This is a safe environment to ask questions and say "yes" or "no" during this traumatic time.

### **What if no one has discussed organ donation with our family and we are interested in our child becoming an organ donor?**

Although it seems natural to ask questions of your care providers at the hospital, they should refer you to the local organ donor program. The law requires that only the people from your local organ donor program may discuss specifics with you. This is due to false information being given to families in the past. Your health care team can contact the right people to provide information to you.

# Organ Donation

## **What if I have been told that my child's condition prohibits her from organ donation?**

Advances in research and medical technology are allowing for increased chances for donation. Continue to ask questions until you have the answers you need.

## **What if I do not want to have my child donate tissues or organs?**

Your decision will be respected. You are not obligated to donate and you must do what feels right to you and your family.

## **What if my child was registered as an organ donor, but we have decided against donation?**

Again, the decision is yours to make and changing your mind is okay.

## **What other questions do you have regarding organ donation?**

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*Information in this section was supplemented by LifeCenter NORTHWEST.*

*[www.livinglegacyregistry.org](http://www.livinglegacyregistry.org), 1-877-275-5269 or*

*email: [info@lcnw.org](mailto:info@lcnw.org) for more information*

## Organ Donation

After you have discussed organ donation with the right professionals, who could you talk to, to make the decision about organ donation for your child? \_\_\_\_\_

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*“Brandon’s tragedy wasn’t going to change. He was able to help over 50 children and adults across the country, and allowing for him to be an organ donor gave other families a chance to overcome their tragedy. For me, this was very important.”*

– Shirley

## Helping caregivers know my child

13

Tell your caregivers about your child, her hobbies, her friends, her favorite book, her favorite toy and funny stories that show her character. No matter how busy your doctors and nurses look, they will want to know about your child when she was healthy.

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What would you most like to have your health care team know about your child?

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(Additional writing space is on the next page)

*“Lissy spent so many years in the hospital and had gotten to know her nurses pretty well, but in her last days, Lissy was up in the intensive care where nobody knew her. Helping to introduce Lissy allowed her team to get to know her.”*

— Resa



**Tip:** Make an “All About Me” poster with pictures of your child when she was healthy.

## Helping caregivers know my child

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*"It was comforting for me to know that the nurses cared about Brandon. They asked me questions about his likes and dislikes, and what his personality was. I enjoyed telling them about Brandon."*

— Shirley

**Tip:** Put up signs in the room to notify your health care team about your child's likes and dislikes...

- Keep medical talk away from the bedside
- Talk to me first before "doing"
- Introduce yourself to me even if I look like I am sleeping
- I like music playing near me

# The Decision-Making Tool

## *for Comprehensive Care Planning*

Family-Centered Care Team Communication with “the DMT”

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[palliative.care@seattlechildrens.org](mailto:palliative.care@seattlechildrens.org)

**Children’s**  
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**Tip: Use the Decision-Making Tool when you will be having a care conference with your child’s health care providers.**

## The Decision-Making Tool: An Introduction for Families

Children with serious health conditions and their families have a great deal of information to consider and many decisions to make regarding care. Regular discussion and care planning with their care team can be very helpful. Children's Hospital staff might suggest a care planning meeting to you, to make sure that your family is at the center of the decision-making and care planning for your child, and that your care team can best hear and respond to your child's needs. The meeting can include your child, family members, hospital staff, your pediatrician, home care nurses and therapists, alternative health care providers, school personnel, spiritual advisors, and any others you wish to invite. It can be used when your child is diagnosed with a new condition, when you have decisions to make about treatment options, planning for discharge, or how to approach your child's care in the future. A person at the meeting will take notes and assist with the discussion to make sure that all aspects of your child's care and situation are discussed. The Decision-Making Tool ("the DMT") is a form that is used as a discussion guide.

### What are the benefits of a DMT care-planning meeting?

- Your family's voice is directly heard—it asks about your belief systems, questions, expectations, plans—what is important to you and your child. Your care team won't have to assume what you want, how to work with you, or how to best care for your child.
  - The DMT structure provides the staff with a much larger picture about your child and his or her care than they might otherwise get. It includes much more than just the medical picture.
  - You get to tell your story and know someone is listening and sharing information with the rest of your care team. The DMT form is reviewed by you and then distributed and placed in your child's chart.
  - It gives you a structured way to reconsider and update the plan when changes happen. You can track changes when reviewing a series of DMTs—each one gives a "signpost"—a way to see what you were basing your decisions on at that time. You and your care team can review those signposts to see how your child's condition has changed and to make changes in his or her care.
- It provides a structure to talk about yesterday and tomorrow, not just the usual problem-oriented approach of addressing today's situation.

### What do families say about the DMT?

- “We went from being very scared and not knowing what to do, to having a roadmap for what could happen in the different possible situations, and feeling very confident about the possibilities.”
- “The DMT helped define things – helped us make decisions, understand the choices and options.”
- “The DMT gave all the providers something concrete to work with. We could communicate our expectations.”
- “The DMT allowed discussion in a non-threatening way. It gives you a structure to talk about difficult things.”
- “The DMT helps all the people in the care team be on the same page. They all know what my husband and I would be choosing in a given situation. The clarity is a positive. It brings some options out that we wouldn’t have considered otherwise, and we get more information on them.”

- “It is extremely helpful to sit down and break down all the issues little by little. We are able to identify what would help and what we should do... It is helpful to review step by step what you’ve done to help your child. Otherwise you lose track of what you’ve done to get here.”

**Tip:** The following pages of the Decision-Making Tool may be copied off to help you during care conferences with your child’s health care professionals.



# The Decision-Making Tool (Explanation)

18

**Patient Name:**

**Prepared by:** Person recording the discussion

**First DMT**

**Date:**

**Present:** Names of all participants, with titles,

**Update**

**Length of Visit:**

for future reference

**Physician of Record:** Primary or specialist

**Care Coordinator:** At clinic and/or at home

## History of Present Illness

In this section, a brief description of your child's medical history and present symptoms and status is recorded.

### Medical Indications

This box contains information about your child's diagnoses, symptoms and treatments. Each diagnosis or symptom is described, and each treatment option discussed in the meeting (either currently used or possible) is listed, along with the risks and benefits for each one.

- Description of diagnosis or symptom #1:

Treatment option(s):

Benefits:

Risks:

- Description of diagnosis or symptom #2:

Treatment option(s):

Benefits:

Risks:

### Patient Preferences

This box contains your child's and family's preferences and goals and choices. This includes how you prefer to be informed by the care team, how you like to be involved in the decision-making, and your goals for this discussion. It also includes your preferences and current thoughts or decisions about each of the specific treatment options discussed in the Medical Indications box.

If your child is too young or unable to express preferences, or if you have decided that they will not be a part of the care planning meeting, you will state your understanding of your child's preferences and your own preferences.

The DMT, developed by the *Pediatric Palliative Care Consulting Service* at Children's Hospital and Regional Medical Center, Seattle, is adapted from an ethical decision-making model developed by Albert Jonsen, Mark Siegler and William Winslade in their book *Clinical Ethics* (McGraw-Hill, 2002, fifth edition).

# The Decision-Making Tool (Explanation)

## Quality of Life

The things that give value and meaning to your child's life are written in this box. What does your child love to do? What gives your child comfort? Think about:

- Important activities
- Important relationships
- Important possessions
- Important goals and hopes
- Things that make your child who he or she is
- Things that contribute to your child's emotional well-being
- Things that contribute to your child's spiritual well-being

Also listed here can be the things your child does not like

## Contextual Issues

The physical, social and spiritual parts of your child's and your family's daily life are written here. This includes all the non-medical information that affects your child's health and health care.

- Home environment  
Who lives in your home, their names and ages?
- Important relationships  
Are there physical restrictions in your home: for example, are there stairs your child cannot climb?
- Who is your child's primary caregiver?
- What extended family and friends make up your support system, and in what ways do they help?
- How do your cultural and spiritual beliefs and needs affect your child's health care?
- Is there any family health history related to your child's condition?
- Does your child receive alternative health care therapies?
- What are the various needs and opinions of your family members and professional caregivers?
- Who are the members of your child's health care team?

## The Decision-Making Tool (Explanation)

**Patient Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

### Discussion

This section documents the discussion between the health care team, your child and your family. It will describe how the things in the boxes above were discussed, what things were decided in the meeting, and what issues you might still be considering or have questions about. It will show how your child's and family's preferences, goals, and all the aspects of your life lead you to the decisions you are making about your child's care. This section can contain the plan of care that is decided upon, with details to follow below.

### Plan

The plan of care can change as your child's and family's needs change. It can be updated when you request, and/or when your child's medical situation changes, when your family's situation or decisions have changed, or when your child's care team has new information for you. Each action item is written, along with the person who has promised to do it and when they should have completed the action. You will review the DMT once it is written, making any corrections necessary. Then your child's physician signs the DMT, each member of the team receives a copy, and it is placed in your child's medical chart.

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**Action:**

**Who will do:**

**By what date:**

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Physician Signature: \_\_\_\_\_

Date: \_\_\_\_\_

The DMT, developed by the *Pediatric Palliative Care Consulting Service* at Children's Hospital and Regional Medical Center, Seattle, is adapted from an ethical decision-making model developed by Albert Jonsen, Mark Siegler and William Winslade in their book *Clinical Ethics* (McGraw-Hill, 2002, fifth edition).

# Decision-Making Communication Tool

**Patient Name:** \_\_\_\_\_ **Prepared by:** \_\_\_\_\_  **First DMT**  
**Date:** \_\_\_\_\_ **Present:** \_\_\_\_\_  **Update**  
**Length of Visit:** \_\_\_\_\_  
**Physician of Record:** \_\_\_\_\_  
**Care Coordinator:** \_\_\_\_\_

## History of Present Illness

In this section, a brief description of your child's medical history and present symptoms and status is recorded.

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The DMT, developed by the *Pediatric Palliative Care Consulting Service* at Children's Hospital and Regional Medical Center, Seattle, is adapted from an ethical decision-making model developed by Albert Jonsen, Mark Siegler and William Winslade in their book *Clinical Ethics* (McGraw-Hill, 2002, fifth edition).

## Decision-Making Communication Tool, Page 2

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### Medical Indications

### Patient Preferences

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## Decision-Making Communication Tool, Page 3

**Quality of Life**

**Contextual Issues**

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# Decision-Making Communication Tool, Page 4

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**Patient Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Discussion

## Plan

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# Decision-Making Communication Tool, Page 5

**Action:**

**Who will do:**

**By what date:**


Physician Signature: \_\_\_\_\_

Date: \_\_\_\_\_

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Encourage  
Comfort

HOPE

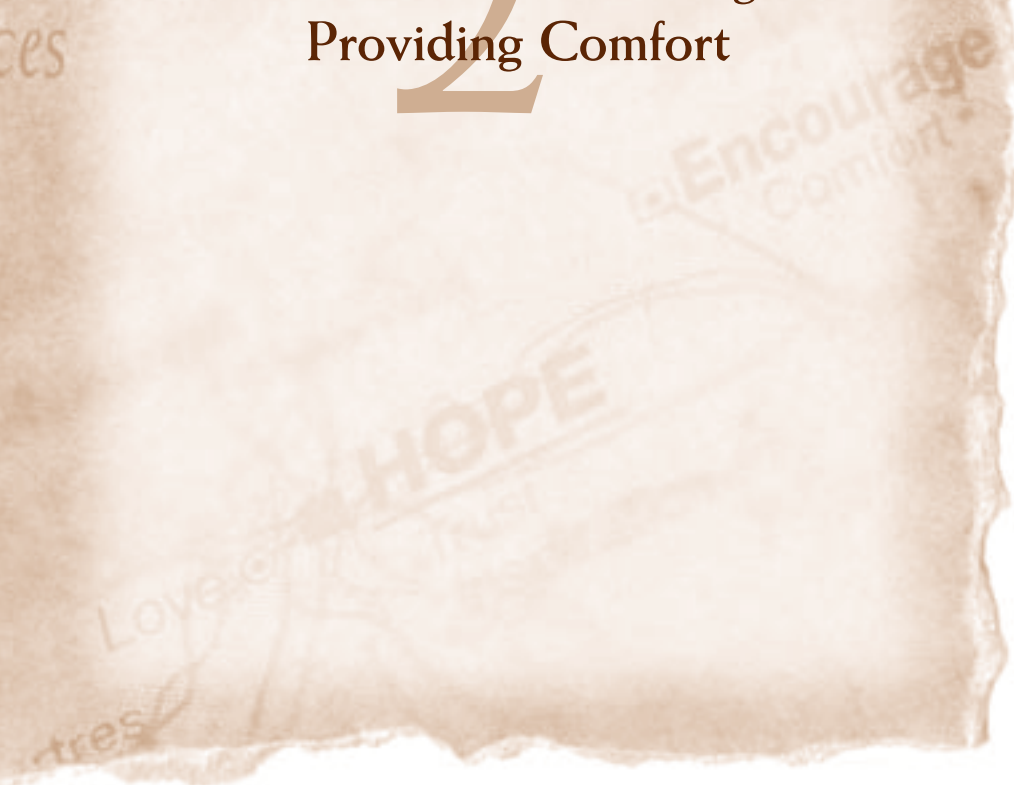
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*Comfort Care*

*Options and Choices*

*Creating Memories*

**2**  
New Focus from Curing to  
Providing Comfort



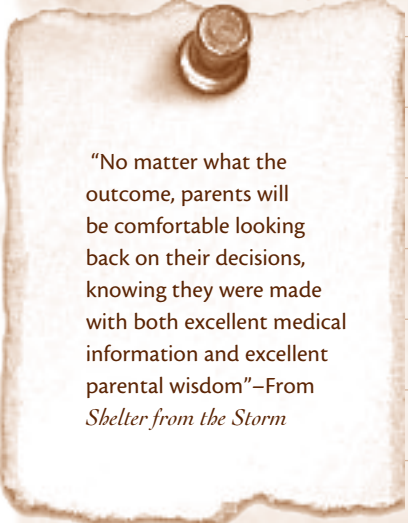
## New Treatment Plan

Together with the health care team (and perhaps \_\_\_\_\_  
with your child) your family has decided to change \_\_\_\_\_  
focus of treatments from curative to comfort \_\_\_\_\_  
treatment. How will you and your child's team \_\_\_\_\_  
accomplish this new treatment plan? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



"No matter what the outcome, parents will be comfortable looking back on their decisions, knowing they were made with both excellent medical information and excellent parental wisdom"—From *Shelter from the Storm*

Encourage  
Comfort

HOPE

Love

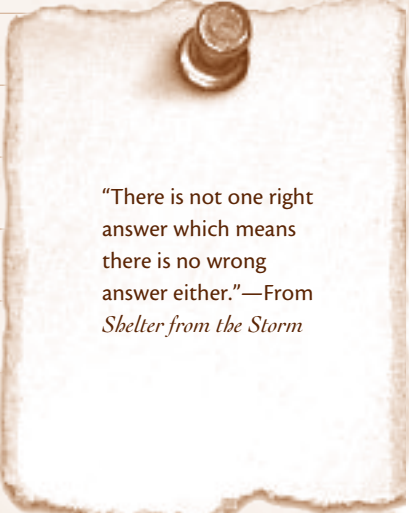
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## "Second guessing" your choices

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Other family members and friends may second guess your decisions to change to *comfort care*. Remember that he is your child and that you are doing the best for him, even if it means allowing him to die. To take the burden away, request that the medical team meet with your family members.

Write about how your family and friends are or are not supporting you and how this makes you feel...



"There is not one right answer which means there is no wrong answer either."—From *Shelter from the Storm*

# Options

### What if I feel that my child is physically suffering?

Discuss issues of pain with your child's doctors and nurses. If you feel that your child needs more help, the *Pain Service* within your hospital and the *Palliative Care Service* are excellent resources to tap into.

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## Options

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There are many ways to bring peace within your family. The sample below is just one way a family was able to bring closure to Leslie's death. Other options include having your child baptized, performing cultural traditions or having a religious ceremony. Make your health care team aware of your desires for your child, as they can help with your needs.

What are your wishes for your child and your family? \_\_\_\_\_

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*"No wish is too much to ask for! I helped a family make the experience of letting their daughter go a little bit easier by listening to their needs. Their dog was talked about much throughout the time I was taking care of their daughter. There was a deep feeling of sorrow within the family that their daughter was not going to be able to say good-bye to Hank... I made arrangements for the dog to be brought into Leslie's room and Hank was brought, on leash, to lie on Leslie's bed. The closure that was felt by fulfilling one small request was profound." (Names have been changed for privacy)*

— Cindy Sloan, PICU nurse

# Options

**If you wish for your child to die at home, discuss the options with your health care team... what did they say?**

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**What details would need to be worked out to allow your child to be brought home?**

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Encourage  
Comfort  
HOPE  
Love  
treasure

# Options

How did you feel about the answers that were given to you? \_\_\_\_\_

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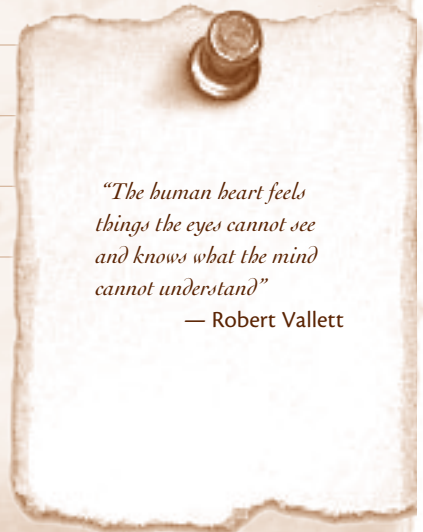
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*“Thankfully, one home health nurse told us in our final weeks of being in the hospital that once we had left the hospital, if we called 911, we had to have a doctor’s signed statement on hand to show the EMTs, so they would not prolong life. As a concerned parent, I wanted to help ease the pain, not to prolong life. That’s a huge difference in the care provided by a 911 technician.”*

– Robin



*“The human heart feels things the eyes cannot see and knows what the mind cannot understand”*

— Robert Vallett



## Options

**Do you want to get into bed with your child – is this possible? Do you wish to hold your child in your lap – is this an option for you?**

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**Do you and your family need some time alone with your sick child? Do you need to ask that phone calls be held, that visitors be limited or even stopped for a period of time?**

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**Do you want time together with your child, family and friends? Can arrangements be made for a number of people to be present at once?**

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**What else can be done to help you and your family?**

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*“Remember that there are alternative death transitions, such as using harp music, special lighting, turning off certain monitoring machines and eliminating medications that are no longer needed. You have choices in these matters.”*

– Robin

## Talking to your child about death

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It is important to recognize that all children are unique in their understanding of death and dying. This understanding depends on their developmental level. It is important to use care and judgment when explaining death to your child. The information on the following pages are for children between the ages of 3-18, but all children are different. It is important to consider your child's unique cognitive, emotional and developmental level before talking about death. Ask for guidance from trained staff if needed.

### Developing an understanding of death

**Infants:** They may understand that you are sad, but have no real understanding of the meaning of death.

**Toddlers:** It is important to remember that toddlers cannot understand what they cannot see. They are affected by the emotions of those around them. They begin to possess early developmental understanding of grief and mourning, but perceive death as temporary.

**Preschoolers:** Death is not seen as permanent to this age group, but as reversible or temporary. It is important to talk in concrete, simple terms due to magical thinking. For example, they may think their illness/dying is punishment for something they have done wrong.

**School-age:** Children at this age start to understand that death is permanent. They understand cause and effect of death. For example, if a plane crashed, people could die. It is important to talk in concrete terms and provide realistic connections.

**Teenagers:** Most teenagers understand the full meaning of death. They know that death is final and that eventually everyone dies. Teens have a difficult time emotionally coping with death. They often withdraw from family and rely on their friends for support.

## Talking to your child about death

### Tips on talking to your child about death

- Talking about death does not make it happen.
- Allow your child to talk about fears, anger, and joy.
- Begin by asking your child, *“What questions do you have?”* and *“Is there anything you are afraid of?”*
- Listening is an important key in helping children cope with dying.
- Accept their feelings no matter how difficult it may be.
- Explain death to your child in a way that they understand and always be honest. If you are having trouble with this, ask if your hospital has a child life specialist or a social worker who can help you.
- Let her know you will be there as much as possible.
- Be consistent by showing your child affection and support.
- Ask her what wishes she would like fulfilled before she dies.

### Involve your child in decision-making

Allow children to be part of the decision-making about their medical treatment and wishes. A simple example is: Do they want the red or blue bandaid? Children are very aware of their body and often know when they are dying even before parents and medical staff do. Your child knows what hurts and what is worth continuing to fight for. Decisions are best made with mutual respect and teamwork between child, parent, and the medical team. For example, a teenager may want to take control of her illness. Allow her to do this, as difficult as this may be, as it will be the only growing up she will ever do.

Allow your child to write a will to leave personal items for loved ones and friends.

### Common fears and feelings your child may be experiencing

- Being alone at the time of death
- What will happen to the families they leave behind
- That they may be in pain

# Talking to your child about death

- That their illness is a punishment for something they did wrong
- Burdening their family with emotional and financial stress

## Ways to help children address fears

Take advantage of professionals who are trained to help children express fears. Child Life Specialists, Social Workers and Chaplains are all great resources when helping your child. Some great ways for your child to express fears are through talking, drawing, playing and writing. Reassure them honestly and in a comforting manner. Everyone should try to talk about their feelings and fears about the illness. Open discussion also allows the sharing of anxieties and the accomplishment of important goals.

## Permission To Die

Children are very sensitive and aware of their parent's sadness. They worry about hurting loved ones who are left behind. As a result, children may cling to life. For some children, it is very important to receive permission to die and reassurance that loved ones will be okay.

## Limit Setting

Continue to set limits with your child by parenting and keeping to the rules. This provides a sense of normalcy and discourages children from feeling a sense of being out of control.

## Other ideas of talking with your child:

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Encourage  
Comfort

HOPE

Love

## Making memories in the last hours

### While your child is still alive, make memories

- Take a lot of pictures or videos
- Save a lock of hair or fingerprints
- Record her voice
- Have him draw a picture or write for you and do the same for him
- Invite friends in
- Tell favorite stories
- Ask if your child has things she'd like to do (talk with Uncle Steve, see her friend Grace, listen to the Dixie Chicks, meet with a spiritual leader... the options can be endless)
- Share your special memories with each other, the fun and favorite stories

### Children need time to play.

Encourage and allow your child to continue with normal activities. Your child may want to fulfill a wish such as:

- Having a slumber party in his room
- A "picnic" with his friends

- Riding his bike one last time (even if it is with a lot of help)
- Drawing a picture and having it framed or seeing a special someone for the last time

Each child will have his own wishes and hopefully you can work with him to make realistic goals for his condition. Organizations such as *Make-A-Wish* 1-800 722-WISH are a great way for a child to make a wish come true.

Children as young as three years old are often aware that they are dying without having been told.



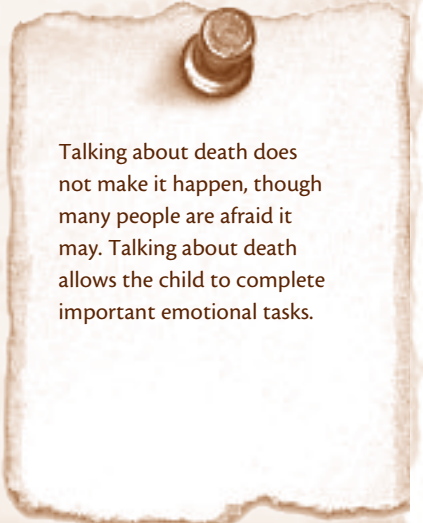
## Writing a Will

For some children facing their own end of life, making some plans helps them feel in control of an event that they feel is out of their control. Some children feel comforted by planning whom they want with them, to hold them, possessions they want to hold, even what they want to happen to their toys/belongings after their life ends.

The following child “Stephanie” (10 years old) spent years in treatment for a brain tumor. When her tumor came back and the doctors told Stephanie the risks of surgery to remove it, Stephanie decided she didn’t want to continue with any more treatment. She wanted to go home. She asked her Child Life Specialist before she was discharged to help her write her will. They looked at a lot of different specialty

scrapbooking papers and she chose one that had a very subtle, airbrushed rainbow on it. She was very tired then and asked for help to work on the wording. However, the next day Stephanie had already written her will.

The following is Stephanie’s will to hopefully give you some guidance with your child...



Talking about death does not make it happen, though many people are afraid it may. Talking about death allows the child to complete important emotional tasks.

## Writing a Will

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*My Last Will and Testament By Stephanie*

To my Papa, I hand him down my Huskie Dog

To \_\_\_\_\_ my little sister I hand her down my toys

To \_\_\_\_\_ my big brother I hand him down my VCR

To my Dad I hand him down my DVD player

To my Grandma I hand down my stuffed animals

To my friend I hand down my CDs

To my Aunt I hand down my glass dolls

To my Grandma I hand down my jewelry boxes

To Uncle I hand down my Rose Bear

To my Mom I hand down my baby blankie

A few days after Stephanie wrote her will, she died at home.



## Memories

**Would you like to help bathe your child? You can bring in special soaps that remind you of your child.**

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**What about a lock of hair, your child's handprints or footprints? Are these things you would like to have with you?**

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**Would you like help in starting a memory album or journal for your child?**

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*"A very special nurse gave me guidance as to how I could take control of Brita's final hours with us. After death is established, there isn't any rule that says you leave and the staff takes over. It is perfectly all right to pick up your child, hold them, rock them, etc. as long as you wish. There is a tremendous closure in bathing their body for the last time and actually touching the coldness and stiffness that is death. You are in control here, take as long as you need."*

– Robin

# Memories

What other mementos can the staff, family or friends help you create?

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## Memories

How do these ideas make you feel? What can you cope with and what is too much for you? Know your limits and go with what “feels right,” not what is “expected.” It is okay to make your wishes known.

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*“Every once in awhile I pull out Lissy’s lock of hair when I can’t remember exactly the color. It was something I didn’t think I would want and a friend of mine encouraged me at the time of Lissy’s death. Now I am so grateful.”*

–Resa

*“A baby’s death is different than an older child’s because the only memories parents of infants may have are those created in the hospital.”*

–Linda P

**Tip:** Talk to your child, cuddle your child and let her know you will be okay. It is so important for someone dying to know those they leave behind, especially their parents, will be okay.

## I feel paralyzed by my fear

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*Name your fears for today and the days and months ahead...*

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*"I didn't think I wanted pictures of Lissy when she was so sick. Now, when I ask myself why she had to die, I can look at the pictures with all of the machines and remember how sick Lissy was."*

– Resa

## Choices surrounding the death of your child

When you and the health care team have decided to allow a natural death you have choices.

Ask if the gowns and masks can be eliminated if these were previously needed for your child's condition.

- Can the lighting be turned down?
- Can favorite music be played?
- Can we decide who is present in the room?
- Can we stay as long as we want?

Would you like to be present when the machines and medicines keeping your child alive are stopped?

Your needs are highly respected during this time. Let your team know what you and your family's wishes are.

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**Tip:** If you decide to be present, there will be someone with you to answer your questions. You may request a specific nurse, doctor, social worker, hospital chaplain, or personal spiritual counselor to be with you during this time.

## Choices

47

*During the death process you are in control about how much information you receive from your team. You can ask for step-by-step descriptions of what is happening with your child's body: Medicines being given to help keep your child stay comfortable, when medicines and machines are being stopped, how each change will affect your child.*

**Communicate your needs. What do you feel you and your partner would like?**

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**What scares you the most about taking away life support?**

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*"Zachary's care had escalated so fast and we were completely out of control, not participating in the decisions about his care and unable to be an advocate for him. Now hospitals are attempting to include families as part of the team so there are more options for you. As an individual and as a couple, you must listen to your gut instincts about the amount of information you can handle and what you want to bear."*

– Linda C.

# Choices

**What questions can be answered to help you and your family through this time?**

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**How is your health care team going to make your child comfortable?**

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Comfort

HOPE

Encourage  
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# My child's health care team

**Name**

**How they helped my child**

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**Tip:** Have friends and family help you with this page so that you have the names of those who helped care for your child. You may want to remember or thank them later.



Comfort

Love

HOPE

Encourage  
Comfort

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Last Moments

51

Surviving Children

Reflections

## When My Child Dies

*We trust that beyond the absence, there is a presence.*

*That beyond the pain there can be healing.*

*That beyond the brokenness, there can be wholeness.*

*That beyond the anger, there may be peace.*

*That beyond the hurting, there may be forgiveness.*

*That beyond the silence, there may be compassion.*

*That through compassion, there may be understanding.*

*That through understanding, there is love.*

Author Unknown

## Last Moments

**After your child has died, you may want to have something special for your child to wear at the hospital. What favorite outfit do you have for your baby? What are your child's favorite clothes? A baseball jersey? A ballerina costume? Red shoes? A favorite t-shirt or hat?**

**Is there a special blanket or favorite toys/items to leave with your child?** \_\_\_\_\_

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**Ask questions about what your child will look and feel like after she dies. How do you want to see your child for the last time? It is okay to leave right after she dies, and it is also okay to stay in the room for as long as you need.** \_\_\_\_\_

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Encourage  
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# Last Moments

What do you want to remember about the last moments you shared with your child?

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*“I struggled with caring for myself during this time. I made sure all of Brandon’s friends had help... counselors were set up at the school, the kids could come over to my house and talk with me, but what I didn’t realize was this was my way of coping. Everyone else came first in my life. Now I make sure to take really good care of me.”*

– Shirley



**Tip:** Tuck away something (piece of clothing, earrings) that you had the last time you were with your child.

## Last Moments

### What happens to my child's body after I leave the hospital room?

Your child's body will be taken to the hospital morgue. You may take several days, if needed, to make plans for a funeral home. Your child's body will be kept in the morgue until these decisions are made.

### May I take my child's body from the hospital?

There is a process you must follow and each state has its own guidelines. Ask your hospital staff to assist you if you are interested.

### What if I cannot afford a funeral home?

The hospital staff can contact a social worker or chaplain to help you explore ways that are comfortable for you.

- Please know that funeral homes are a business. The hospital staff may give you options in choosing the best places for your family. It helps to learn about the options different funeral homes offer in your area.
- Be aware that if cremation is desired, not all funeral homes are equipped to do this.

- You may ask the funeral director to inform others if you prefer donations be made to a favorite charity or fund.
- Foundations can easily be created through an attorney. Instead of flowers/gifts, you may have money donated for a one-time or ongoing gift to a specific cause. This can be a great task to give to a close friend or family member who would like to help.
- You may want to request certified copies of the death certificate. If needed, most people accept copies of the death certificates.
- Find out from the funeral director the newspaper deadline to submit an obituary.
- Talk to your spiritual leader if you wish for them to lead the funeral.

**Tip:** Do you need help in making funeral arrangements? Ask your social worker to help you with resources. Sometimes there is financial support available for those in need. There will be a staff member available if you would like guidance and support.

## Last Moments

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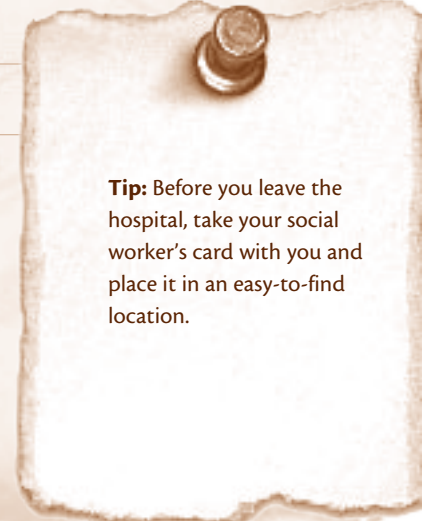
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*"We had a funeral service for Brandon and we also had a celebration of his life. As people were coming over to visit before the celebration, they were given big pieces of white poster board to write special memories and display pictures. We put them up around the boat we took out to spread his ashes and we were all able to walk around and cry and laugh, re-living Brandon's memories."*

—Shirley



## How will you leave your child for the last time?

Sometimes a member of your child’s health care team may offer guidance and other times a family member or close friend can step in to help you. One suggestion is to begin calling close friends and family members if you are able.

Who can you call to be with you?

Is there a staff person who would be available to help you make the first call?

Do you want to designate someone else close to you to begin making phone calls?

Who will help you get through each moment after you leave the hospital?

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*“After Lissy died I needed to know my daughter would be transported with care. I wanted to ensure that when my daughter was away from me, those that were with her would be PRESENT and not talking about the baseball game last night. I pinned a note on her shroud that said... Very Important Person, please transport me with dignity.”*

– Resa

*“We shall draw from the heart of suffering itself the means of inspiration and survival”*

**– Sir Winston Churchill**





# Who needs to be notified of my child's death?

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strength

HOPE  
Encourage  
Comfort  
Loyalty  
Trust  
Respect

## Caring for surviving children

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The death of a child strikes at the very heart of a family. Bereaved parents often feel helpless to provide guidance and comfort to their surviving children because parents' emotional and physical resources are severely stressed. Children are often referred to as the "forgotten mourners" because the attention of family members and friends is directed toward the parents.

Although surviving children have feelings of grief similar to those of an adult, they often express those feelings differently because they are young and do not have the same coping abilities as adults. They may seem outwardly confused and defensive, and unwilling to share their grief with their parents, preferring to depend upon their peer group or others for support.

**Tip:** Plan a memorial "Celebration of Life" in which your surviving children and friends can participate, making them feel a part of the family's grieving process. You all may find new memories and fun things about your child during this process.

A surviving child is reacting to the loss of a sibling and to the changed behavior and interaction of parents and others who are close. Reassure your children that the depth of grief you are feeling does not lessen your love for them.

The following suggestions come from bereaved parents, surviving children,

and professionals to assist bereaved parents in understanding and meeting the needs of their surviving children.

### Caring for surviving children

Be aware of your child's level of understanding as it relates to the death of a sibling:

- 0-18 months old—has no conception of death, but may respond to parental reactions to the loss.
- 18 months-3 years old—possesses the early beginnings of grief and mourning, but perceives death as temporary.
- 3- 5 years old—continues to see grief as temporary, with difficulty understanding the permanence—needs concrete explanations of what death means.
- 6-8 years old—understands their sibling will not return and death is universal (it could happen to me).
- 9-12 years old—understands the reality of death and is curious about biological aspects of death and details of the burial.
- 13 years and older—fully understands the concept of death.

## Caring for surviving children

Explain truthfully to your children, on a level they can understand, what caused the death of a sibling. Answer questions simply and directly, giving answers to build on later as the child ages.

### Explaining the Concept of Death

To avoid fear in a younger sibling that he or she may also die, explain that there are reasons why a person will die: That person is very, very, very sick; that person is very, very, very hurt.

Oftentimes, religious sentiments intended to comfort children can be misinterpreted, causing confusion.

Avoid phrases that can be easily misunderstood by children:

- The sibling who died is not asleep
- God did not come to take the sibling to heaven
- The child was not “called home.”

### The Sibling Relationship

Your surviving children had a close relationship with their dead sibling. There were times of great love and there were times of great anger. Children often feel guilty about these times of anger and may even feel that in some way this caused their sibling's death.

### Parental Role Modeling

Children learn how to express grief by observing their parents' mourning process. Therefore, it is important that parents acknowledge their child's death, display appropriate emotions, and give their surviving children permission to do so, as well. While you should not be afraid to show an appropriate level of emotion in front of and with your surviving children, you need to reassure them that although you are grieving, you will still be able to take care of them. If they can see the extent of your grief, this will confirm their own feelings, that it is okay for them to cry, be sad, show anger and even laugh.

Parents often idealize their dead child, causing siblings to feel they can never live up to the standard of love lavished upon their sibling's memory. Parents should take care not to make comparisons with surviving children that could lead to feeling that they are unworthy. Surviving children might feel the parents wish they had died instead.

Reinforce the positive things your surviving children do. Spend quality time with them.

While it is difficult, parents must balance a fine line not to be overprotective or overly permissive. Routines should be continued whenever possible.

## Caring for surviving children

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Many children find it difficult to talk openly about their feelings with their parents. This does not mean they do not want your input. When your children do open up to you, if even briefly, listen carefully to what is said and the concerns that are voiced. Do not yell, criticize, or judge if they say something you consider off-base or out-of-line. This may be your only chance to gain their confidence.

### Some Typical Reactions

Children often find it easier to “mourn at a distance”—to show little emotion at a sibling’s death, only to mourn in private away from other people. Tears may still appear at the most unexpected times. Use these openings to support them in their grief and acknowledge how difficult it must be for them to lose their sibling.

- Younger children may at first make jokes or continue normal play as a distraction. This is not abnormal nor reason for concern. Do not scold them.

**Tip:** Have children write a letter or draw a picture to be buried or cremated with their sibling.

- For those a little older, it’s okay to cry and feel depressed. They’ve lost a great deal.
- To copy some of their brother’s or sister’s habits and interests, while still being themselves.
- To live “in the past” for a while to keep alive the memories.
- To forgive themselves for fights, arguments, and mean things they said or did to their brother or sister.
- To go on living.

### However, watch for destructive reactions:

- Use of drugs or alcohol.
- Acting out of frustration through reckless driving or skipping school.
- Doing things out of anger to hurt others because of the pain they themselves are feeling.
- Experimenting with sex just to feel close to someone.
- Discontinuing activities that meant so much to them.
- References to suicide.

## Caring for surviving children

### Suggestions for helping your children

- Children need parental support and a chance to be heard, acknowledged, and understood if they are going to work through the grief process.
- Share the belongings of the child who died, perhaps giving each surviving sibling something “for the moment” and something to put away for adulthood like a photograph, favorite book, CD, or piece of jewelry.
- Help your children to channel their grief into positive activities such as drawing, writing in a journal or diary, and reading. Seek their advice in ways they may want to signify their siblings such as creating a memorial fund, and help them accomplish these goals.
- If you find, after a time, that your children don't seem to be adjusting to their new lives, don't be afraid to encourage them to talk with a qualified school counselor, a psychologist or psychiatrist who specializes in bereavement.

Permission to reprint given by:

The Compassionate Friends,  
P.O. Box 3696, Oak Brook, IL 60522-3696,  
Phone toll free: (877) 969-0010  
[www.compassionatefriends.org](http://www.compassionatefriends.org)


*“Talk with your living children truthfully. Do not deny them the action of experiencing the death process. We always talked ‘Life’, but when that wasn’t going to be true, we talked ‘Death’. The ‘healthy’ children have definitely been in the shadows, and have been dealing with challenging issues of identity and competency all through their sibling’s illness. There is a lot going on and the parent who is grieving is usually not the one who should be helping their own children. There are support groups for children dealing with those losses. Hospice offers a support group for children, and [www.grievingchild.org](http://www.grievingchild.org) lists support groups by state. But, kids, agreeing or not, need to have a safe place to share their feelings.”*

– Robin

**Tip:** Use these suggestions to also talk with cousins, friends and other children who were close with your child so that they may be helped with their own understanding and grieving process.

## How are you and your partner deciding to talk with your other children?

63



**Tip:** Make copies and send a general thank you letter/card expressing gratitude to family and friends.

Encourage  
Comfort

HOPE

Love

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## Caring people I want to thank (When I am able)

Name

Name

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**Tip:** Ask someone to keep a record of calls, food, gifts and visitors.



## Friends and Family

65

Allow yourself to accept care from others, as they are comforted when allowed to help. Their help will aid you and your family during this difficult time.

Often people feel unsure of how to help. Friends and family may benefit by healing and finding closure when asked. So when they ask how they can offer support, the following are suggestions to give:

- Listen to you and sometimes don't say anything. Sometimes words are awkward and unwelcome and the presence of your support system is what is important. Friends and family members can acknowledge, rather than minimize, your grief and heartache.
- Go out with you on your first outings so they can answer questions instead of you.
- Help make funeral arrangements and tend to the details.
- Remember your child's birthday and anniversaries of death.
- Use your child's name in day-to-day life.
- Bring meals and help with household chores until you are ready to cope with day-to-day

activities.

- Pray or organize support from your church, temple or spiritual site to sit with you.
- Write special memories of your child and compile them into a memory book.
- Provide financial help—you may not be working and your expenses have piled up. You've been eating out, making long distance telephone calls and now the medical bills are beginning to arrive:
  - gift certificates to grocery stores and restaurants
  - gas cards
  - pay bills
  - organize community donations
  - assist with medical insurance claims
- Sometimes not always asking what they can help with, but learning to anticipate your needs and just doing something for you. You do not need to make any more decisions than you have to and answering "yes" to help may be difficult.



## Friends and Family

Remember: Sometimes you may have to tell people that there are days when talking about your child is too much. Know that it is okay to say, "This really is not a good time for me to talk about this."

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*Silence is okay "True friendship comes when silence between two people is comfortable."*

– Dave Tyson Gentry

*"Encourage friends and family to talk about your child and recall memories. This is helpful immediately after the death and also for the months and years following."*

– Robin



**Tip:** Suggestions to give to friends and family on what to say to you:  
"I'm so sorry"  
"How can I help?"  
"We've been thinking of you so much."  
"Do you want to tell me about \_\_\_\_\_ name of the baby/child's birth? Personality? Likes/Dislikes?"  
"I feel so sad for you."  
"I can't begin to imagine what you're going through, but I want you to know how much I care."  
(Mayo Clinic Complete Book of Pregnancy & Baby First Year/ Mayo Foundation for Medical Education and Research. 1994. First Ed. William Morrow and Company, Inc.)



## Your relationship with your partner

How are you and your partner going to make it through this with each other?

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*"We appeared to be doing 'good.' but I was above ground and my husband was below ground, both managing, and seemingly 'strong.' Then, my brother died seven years after Zachary, and we realized we somehow had never checked-in with each other. We had needed help all along and never realized it."*

– Linda C.

## Your relationship with your partner

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- Remember that every parent grieves differently, but decisions can still be made together.
- You will need each other for support. Try not to spend excessive time away from home or your partner.
- Express care through touch and expression for one another.
- Realize the strain this will place on your relationship and don't be afraid to seek help.
- Think of some symbolic ways to remember your child: planting a tree/bulbs, speaking, establishing a scholarship, planning an annual activity, creating traditions.
- Fundraise in their name.

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*"You are a couple, but you each grieve a separate path. You are both walking the same direction, down the same road, maybe brushing shoulders, but you can't even reach out and hold each other's hands. It is a very individual and separate journey. Do not expect your spouse to see through your eyes, they may never. But accept their way of walking the path and realize that you may never understand how they are processing this death. As difficult as it is, try to not lose sight of your relationship as a committed couple."*

– Robin

*"Grief is a very self-centered, personal emotion and it is important to have respect for others' means of grieving."*

–Cindy

## Reflections

You have done everything you could have done...realizing you may be questioning this...write how you are feeling...

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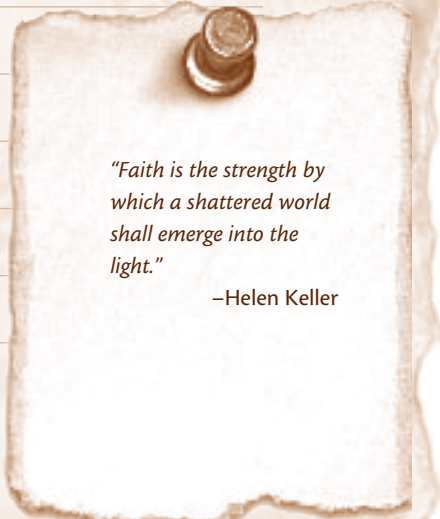
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*"I have kept the bill from Lissy's last hospitalization. Seeing the itemized charges listed out reminds me of why Lissy died when I can't remember how sick she really was."*  
– Resa



*"Faith is the strength by which a shattered world shall emerge into the light."*  
–Helen Keller

# Reflections

You have been a wonderful parent to your child. Of course mistakes have been made, but you have done your best. How will you learn to forgive yourself for the mistakes that haunt you?

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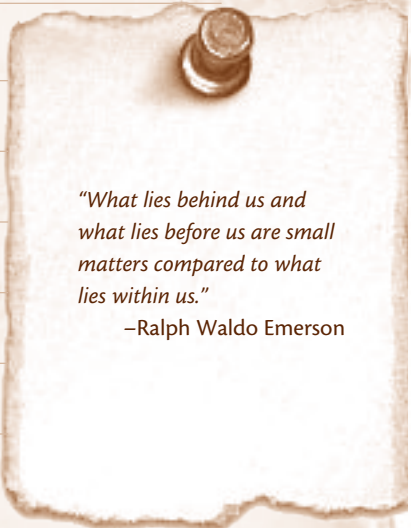
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*“What lies behind us and what lies before us are small matters compared to what lies within us.”*  
—Ralph Waldo Emerson

strength

HOPE

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## Reflections

73

Find a picture of your child. Journal about the picture. What is your child doing? What are you doing? Why is the picture important to your life together? What memories does it hold for you?

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*“Grief, like the ocean comes in waves only to recede and come yet again. But with it comes healing. Memories wash ashore and are bathed by the sun. Grab hold of those memories and let them fill the emptiness.”*

– Joanne Fink



Trust

Love  
tres

HOPE

Encourage  
Comfort

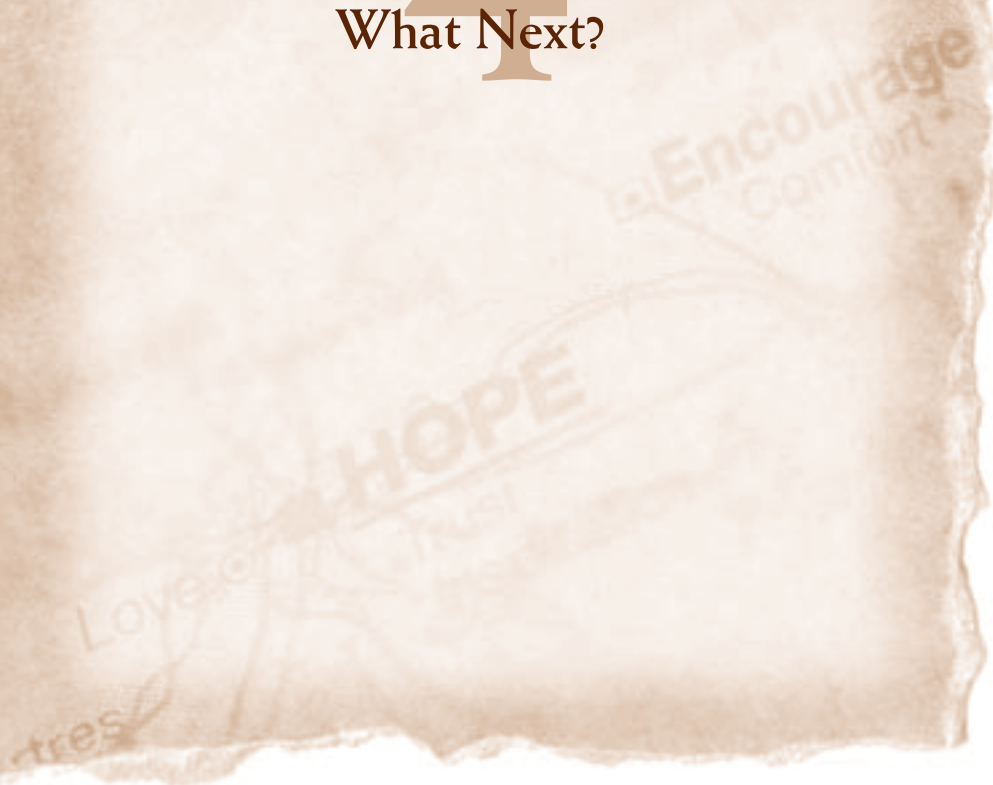
Accepting Help

Support

# 4 What Next?

Small Goals

Steps Forward



## For mothers whose baby died before, during or shortly after birth

Whether or not you were planning to breastfeed your baby, when your milk comes in after your baby has died, it is often an unexpected shock. This may feel like one more thing that is happening to you over which you have no control. You may produce milk if you lost your baby as early as 16 weeks gestation. How much milk you make is dependent upon your individual body, breast stimulation, and the grieving process. Although the average time for milk to come in is 2-3 days after birth, the grieving process can delay that by several days.

When your milk comes in you may experience quite a range of emotions from sadness to bitterness and extreme anger:

*"I had to wear breast pads for 4 weeks. I leaked all over. I thought about my friend who didn't have enough milk for her baby and I had all this milk and my baby was dead. I thought 'When will this ever end?'" – Debbie*

Part of grieving is having opposite feelings at the same time:

*"When my milk came in, I thought, 'What is the matter with my body—doesn't it know my baby is dead? When I was engorged I wished it would go away and stop torturing*

*me. When it went away in only 5 days I was furious it gave up so easily." – Linda*

When you are grieving you may have fears that you think are silly, but you can't stop thinking about them:

*"I was afraid all the milk lumps would permanently clog my breasts and if I ever had another baby I wouldn't be able to breastfeed her." – Diane*

While many women cannot bear the thought of having milk and no baby, others want their milk to come in:

*"My only baby died – I wanted my milk to come in. I didn't want to do anything to stop it. I wanted as much of the full mothering experience as I could have, even if I could never breastfeed him." – Debbie*

For a long time after your baby has died, you may think, dream or feel things that you think are 'crazy.' This is a normal part of grieving:

*"I wake up at night to nurse the baby. I hear her crying and she's not here." – Kim*

## Practical help for breast engorgement

77

Your body will recognize quickly that it does not need to produce milk if you follow a plan like this:

1. Do not express any milk from your breasts – the pressure of too much milk inside the milk ducts causes milk production to stop. If you release that pressure by expressing milk, the breast will make more milk.
2. This pressure, and the accompanying lumpy feel of milk and tissue swelling may be uncomfortable for 3-4 days for most women and as long as 10 days for an unfortunate few. Although you may or may not continue to have some milk after this, it will not be painful and will gradually reabsorb. You may notice a few drops of milk occasionally for up to several months after stopping.
3. During the initial period, several things may help:
  - Wear a tight fitting bra day and night. A sports bra is good.
  - Use cloth covered ice packs or bags of frozen peas, rotating every 20 minutes.
  - Ask your doctor about medicine to relieve

your pain. Most doctors recommend Ibuprofen (200mg) 2-3 tablets every six hours for at least 24 hours to build up a therapeutic level for the tissue swelling and pain.

- When showering, stand with your back to the flow – avoid heat on your breasts.
- Do not reduce your fluid intake – it will not reduce your milk supply and can make you dehydrated.
- If the pressure feels unbearable, you can relieve it somewhat without bringing in more milk by leaning over the sink or a bowl filled with warm water and submerging your nipples only. This will allow some milk to flow out.

You may talk to your doctor about other options.

Breast infections: Although it may seem that your breasts are hot and lumpy during this initial period, it is very rare for a mother to get a breast infection while her milk production is stopping. Call your doctor, however, if you should get these symptoms: fever, headache, nausea and redness in one area of the breast.

*“You are still a parent to your baby that died. No one can take that away from you.”*

– Linda P.

## For mothers whose milk supply is established

If your baby died suddenly, you may choose to gradually lessen your milk supply or stop production quickly. If you want to stop your supply quickly, follow the instructions on the previous page.

For some women it may be easier emotionally to gradually lessen your supply. You can do this by pumping your milk. Start at about 6 times a day for about 10 minutes each time. Each day eliminate one pumping and shorten the pumping time. You may prefer a less structured approach, such as pumping only enough to release pressure and keep your breasts comfortable.

If your baby was hospitalized for a long time or if you pumped extra milk at home, you may have milk that you do not know what to do with. It

is heartbreaking to throw away milk that you pumped to benefit your baby. A few women who have a great deal of frozen milk donate their milk to milk banks. They feel this is one way that they and their baby can help other babies.

### **The Mother's Milk Bank:**

(408) 998-4550, San Jose, CA

### **The Mother's Milk Bank:**

(303) 869-1888, Denver, CO

If you need further lactation help or information, please call a lactation hotline at your nearest hospital.

The information provided on breast care was reprinted with permission from Linda Pugmire, *"The Bereaved Mother: Breast Care"*

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*"Your baby's life had meaning and made a mark on the world. You may want to plant seedlings, make baby blankets and donate them to children's hospitals and shelters, donate infant clothing or begin a charitable fund in your baby's name to emphasize the importance of your baby's life."*

– Linda P.





## Your Baby and Child

81

Other rituals beyond a funeral may be necessary to help you and your family say good-bye.  
What may some of these rituals be?

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*“It took a mother whose baby died after 13 days of age several years to find how she wanted to celebrate this child. Now the family has a birthday party every year for her. Their two children, born after Colleen, each receive a gift. Now this is one day a year that they all smile and celebrate!”*

– Tammy Rondolf, PICU Nurse



## Your Baby and Child

How will your child continue living through you? Write about your child's meaningful traits and how you want to develop these within yourself.

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*"Constantly, I am reminded that I gave birth to another child who did not live. How do I continue to deal with questions about my new baby? Is this your first? When will you have a second child? How many children do you have?" When I am in the grocery store, sometimes I really don't want to say 'Well, actually...' to some complete stranger. But then I feel guilty for not recognizing Parker."*

– Dara

*"I searched for a long time about how to respond to people when asked... how many children do you have? I believe everyone must find their own way to answer, but I say...I have three children. I have a 23 year old son who lives in Boston, I have a daughter, who would be 22 – she died seven years ago, and my youngest daughter is 17."*

– Resa

# Your Baby and Child

*How has your child's life experience affected your spiritual journey?*

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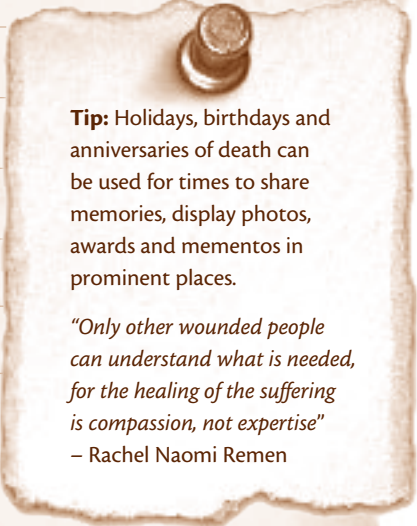
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*"You will be able to help other people through your experience – you have the 'authority' to identify with others who are suffering."*

– Dara



**Tip:** Holidays, birthdays and anniversaries of death can be used for times to share memories, display photos, awards and mementos in prominent places.

*"Only other wounded people can understand what is needed, for the healing of the suffering is compassion, not expertise"*

– Rachel Naomi Remen

# Support

If support groups are not a desire, ask to be paired with another family who has been through a similar experience. Ask the social worker who worked with you and your family what support programs are available.

What other ways of support can help you? \_\_\_\_\_

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*“The key was to get plugged in and not isolate ourselves – I saw isolation as the enemy.”*

– Dara

*“You will never find someone with the exact same experience as you. But someone who has had a similar experience can often be the support you need as you grieve.”*

– Linda P.

## Support

85

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*“The hospital staff has become your support group and family during your child’s entire illness. They are with you through your child’s death. And they are willing to continue that support through the funeral or whatever closure service is chosen. But after that, they are not, and cannot continue to be your support. They have to go back to their jobs. There are still needy children and families at the hospital that demand their attention. And because that is where their job is, they have to let go of you. This is one of the hardest adjustments. You must learn to let go of them, as well as your child. If you have established a strong back-up support system, this is considerably easier, but still very traumatic. Back-ups usually need to be in place in your life before the illness or event occurs, but not absolutely. Some obvious support systems could be your church, school, sport groups, neighborhood, etc.”*

– Robin

*“6-12 months after my child died and the rest of the world moved on I was left feeling alone in a world that did not understand the continuous grief I was experiencing. My circle of friends had never experienced the death of a child. More than ever I found myself needing to be a part of a support group with parents that had lost a child. My advice to other families who are grieving the loss of their precious child, as hard as it may be is to take that first step, and reach out to others in the same situation. We enrolled in a support group with six other couples who had babies who had died and it was the single most important step I made in beginning the long journey towards healing and accepting the death of my son.”*

– Angie

## Support

Small goals are important to get through each day, week and month. Make dates with friends to do an activity such as exercise, a movie, or lunch. Although you may not enjoy these activities at first, continue to create structure in your life.

What ideas do you have to attain small goals? \_\_\_\_\_

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\_\_\_\_\_

*“The grief doesn’t ever get any better. It gets different. Your ‘normal’ has changed. Being kind to yourself is important as there is no right or wrong way to grieve.”*

— Linda C.

*“Writing that first letter to our friends was so hard to do. I used an introduction from a man who had lost his wife and if I hadn’t had help on how to start the letter, I don’t know if our family would have ever sent another Christmas card. It read... ‘This will forever be the first letter written without our beloved...’ Now, when signing our family’s names on cards or gifts, Lissy is included in the signatures with a star.”*

— Resa

## Support

87

Write prayers of your heart and save them to read when prayer seems difficult.

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*“For the first few weeks I was numb, as if there was cotton surrounding my brain. This was my body’s coping mechanism because I couldn’t handle the emotional pain right away. When the numbness started wearing off, the feelings were overwhelming but I was at a point that I could somehow deal with them. When people would say to me ‘you are doing so well’ that wasn’t it at all. I was protected by the numbness.”*

– Linda P



The authors would like to thank the following professionals for their invaluable expertise and guidance with *Life's Toughest Moments*.

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Some of the journal exercises throughout were  
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*The quotes throughout the book are from parents whose children have died. They wish to open their hearts to you by offering advice and knowledge from their personal journeys so that you might find hope, comfort and support.*

**Robin's daughter Brita** lived until the age of 10 years old, after being diagnosed with acute lymphoblastic leukemia in 1996. Blessed as an amazing artist, Brita spent a large amount of time drawing and painting pictures for her friends and family. She loved being active and played soccer and gymnastics. Brita is survived by her mother, father and sister who remember her as the shy little girl who would open up to a special few. Her faith in Jesus and resolve that she would rest in heaven has remained as inspiration to all those she touched while she was here.

**Dara's son Parker** was born with a single ventricle heart. Parker is remembered by the peace and faith God birthed within family and friends during his two weeks of life. He was a blessing to all who met him and who were privileged to pray for him, even though God chose to take him home.

**Linda's son Zachary** was born with a rhabdoid tumor. He died when he was five months old. Zachary's brief life was certainly bittersweet. He was a beautiful baby with a spirit for life, perhaps unaware of how sick he was. Since Zachary's death, Linda has worked to transform the anguish of losing a child to hope by reaching out to others facing the death of someone they love. What began as a mission to understand her grief has become a gift of healing for her. A journey that first felt like a curse and then seemingly a blessing is now a peaceful acceptance of who Zachary was and

who he can continue to be. Linda has realized that Zachary's spirit and love lives on and so will hers.

**Shirley's son Brandon** was 16 years old when he was hit by a car when riding his bike with a friend. Brandon had a love for life and was always looking for the next adventure that would come his way. Brandon was dedicated to his family and friends and was a very compassionate individual. Organ donation is Shirley's own bittersweet miracle that she cherishes every day.

**Resa's daughter, Lissy**, was born with cystic fibrosis, and spent a great deal of time in the hospital. She received a double lung transplant at the age of 9 and enjoyed her new lungs until her death at the age of 15. Throughout her life Lissy's spunk, sense of humor, and appreciation of life were an inspiration to Resa, her family, friends and many, many others whose lives she touched.

**Angie's son Brandon** was such a strong, sweet little baby. Even a year and half later after his death, she is still shocked that she is the mother of a baby who has died. She misses him intensely everyday, but is thankful for the 10 short days she had to spend with him. The death of her son has been incredibly life changing in both positive and negative ways. Brandon's death has brought Angie a newfound appreciation for life and taught her just how unpredictable and unfair it can be as well.

## Resources

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### Books

#### For Parents

- "An Intimate Loneliness: Supporting Bereaved Parents and Siblings (Facing Death),"* by Gordon Riches, Pam Dawson
- "Cancer Pain Relief and Palliative Care in Children,"* by the World Health Organization (Geneva, 1998)
- "Dear Parents: Letters to Bereaved Parents,"* by Joy Johnson
- "Empty Cradle, Broken Heart-Surviving the Death of Your Baby,"* by Deborah David, Ph.D.
- "Help, Comfort & Hope after Losing your Baby in Pregnancy or the First Year,"* by Hannah Lothrop
- "Hospice Care for Children,"* edited by Sarah Zarbock Goltzer and Anne Armstrong-Dailey (Oxford University Press, 1993).
- "Meditations for Bereaved Parents,"* by Judy Osgood
- "Shelter from the Storm,"* by Joanne Hilden, M.D. and Daniel R. Tobin, M.D. with Karen Lindsey
- "The Bereaved Parent,"* by Harriet Sarnoff Schiff
- "The Bereaved Parents' Survival Guide,"* by Juliet Cassuto Rothman
- "When a Baby Dies: A Handbook for Healing and Helping,"* by Rana K. Limbo and Sara Rich Wheeler

#### For Children

- "Cat Heaven,"* by Cynthia Rylant (Blue Sky Press, 1997)
- "Old Turtle,"* by Douglas Wood and Margaret Pike (Centeringcorp, 1992)
- "The Next Place,"* by Warren Hanson
- "The Mountains of Tibet: A Child's Journey Through Living and Dying,"* by Mordicai Gerstein
- "When Dinosaurs Die,"* by Marc Tolman Brown
- "When I Die Will I Get Better?"* by Piet and Joeri Breebaart
- "Badger's Parting Gifts,"* by Susan Varley

#### For Siblings

- "Am I Still a Sister?"* by Alicia Sims
- "Grieving Child,"* by Helen Fitzgerald (Simon & Schuster, 1992)
- "Hi, My Name is Jack,"* by Christina Beall-Sullivan
- "No New Baby,"* by Marilyn Gryle
- "Sibling Grief,"* by Sherokee Ilse, Linda Hammer Burns, Susan Erling Martinez
- "The Fall of Freddie the Leaf,"* by Leo Buscaglin (Thorofare NJ, 1982)
- "The Grieving Teen,"* by Helen Fitzgerald (Simon & Schuster, 1994)

## Resources

### Websites

[www.beyondindigo.com](http://www.beyondindigo.com)—provides grief support, products and services to individuals and companies who assist people who are grieving.

[www.candlelighters.org](http://www.candlelighters.org)—Its mission is to educate, support, serve, and advocate for families of children with cancer, survivors of childhood cancer, and the professionals who care for them.

[www.centering.org](http://www.centering.org)—A grief resource center.

[www.compassionatefriends.org](http://www.compassionatefriends.org)—assists families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.

[www.grievingchild.org](http://www.grievingchild.org)—provides support and training locally, nationally and internationally to individuals and organizations seeking to assist children and teens regarding grief.

[www.bandonline.org](http://www.bandonline.org)—help after a neonatal death

[www.hannah.org/resources/loss.btm](http://www.hannah.org/resources/loss.btm)—Christian support for infertility or the death of a baby at any time from conception through early infancy.

[www.hopingskillscompany.com](http://www.hopingskillscompany.com)—*Hoping Skills*

*Company*, founded by a bereaved parent and a Child Life Specialist, offers products and resources to help children and adults deal with illness, grief and loss. In addition to recommended books, they also have specially selected items and prepackaged coping kits. Extending to you the gift of hope, healing and peace for tomorrow.

[www.hospicefoundation.org](http://www.hospicefoundation.org)—provides leadership in the development and application of hospice and its philosophy of care. Through programs of professional development, research, public education and information, Hospice Foundation of America assists those who cope either personally or professionally with terminal illness, death, and the process of grief.

[www.hospicenet.org](http://www.hospicenet.org)—offers a wide selection of resources by category for children and adults on the questions surrounding death as well as how to cope once the death of a loved one has occurred.

[www.shareyourlife.org](http://www.shareyourlife.org)—the *United Network for Organ Sharing* website.

## About the Authors

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**Jennifer Smith** is a registered nurse specializing in pediatric intensive care with babies and children. Since the beginning of her career, she has advocated strongly for her patients and worked to empower their parents through education and support.

After working at Texas Children's Hospital for three years, she returned to the Pacific Northwest where she continues her nursing career in the pediatric intensive care unit of Seattle's Children's Hospital and Regional Medical Center.

Jennifer lives in Gig Harbor, Washington, and enjoys skiing, running and spending time with friends and family, including her husband, Matt, their daughter Sadie and their dog, Blaize.



**Bradie Kvinsland** is a Certified Child Life Specialist, working with the emotional and developmental needs of acute and chronically ill children and their families.

Bradie has spent her career working at Swedish Medical Center in Seattle, Washington, with pediatric patients in oncology, intensive care, and surgical services. She has created programs to enhance family-centered care and advocates for the needs of children and families through

hands-on clinical work.

Bradie received her bachelor's degree in Family Studies from Washington State University. She resides in Gig Harbor, Washington, with her husband, Eric, and their son, Ryker.

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### Special Thank You to Lana Stahali



Lana Stahali, Ph.D. is a coach on relationships and life strategies and founder of Bounce, Beyond Better and co-founder of Global-HELP.org

Born in 1947 with a then fatal birth defect, I know of the triumphs and the despair of children who struggle to survive. The challenges and heartache of families who watch their child struggle and lose, is a pain unimaginable.

As my friend, Resa Moore, Lissy's mother, says, "God does give you more than you can handle" and, like Lissy, many children lose the

struggle. Their death is an unimaginable devastation to all who care for them.

*When the old die, we may find wisdom in their death*

*When a child suffers, we must find joy*

*When a child dies, we must find inspiration.*

This book, *Life's Toughest Moments*, shows you a path toward healing on life's most difficult journey, the loss of your child. I am grateful to be able to support this gift from Jennifer Smith and Bradie Kvinsland who are both young mother's. Their vision, talents and dedication will make your journey a little more tolerable and help you go beyond your loss with love to find inspiration.

Love of  
HOPE  
Encourage  
Comfort  
Trust  
Patience  
Tenderness



## Contact Us

### We would love to hear from you!

Where did you obtain *Life's Toughest Moments*?

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Why was your child hospitalized?

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What hospital was/is your child in?

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How was *Life's Toughest Moments* helpful to you?

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What is the best advice you could give to another parent?

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What suggestions do you have for future publications and/or website content?

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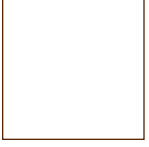
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May we use your comments as a testimonial? If so, do you want to include your name?

Use my comments  (yes)

Use my name  (yes)

Love of Trust  
Encourage  
Common



**Life's Toughest Moments**  
**P.O. Box 2584**  
**Gig Harbor, WA 98335**

Fold Here



\$13.95 U.S.

Health/Family/Inspirational

*"Life's Toughest Moments"* helps families advocate for their child during the end-of-life stage, create meaningful memories and take steps in the first few days after their child has died.

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"When our daughter Anna was dying, I often tuned out whenever her caregivers began discussing end of life decisions. It was too painful to hear out loud, and it seemed like asking questions was admitting that her illness had already defeated her. This book allows a parent to explore the possible scenarios of the coming events in privacy, with an option to close the book whenever it gets to be too much. Even more importantly, it provides ideas for meaningful legacy building and special moments to share, in a time when the parent's mind may be too exhausted or cloudy to come up with them on their own. For us, having small things to share and look forward to with Anna during that time gave us reason to hope. The spark of hope that keeps a parent going through a child's illness does not have to die when a child is dying. Having hope for a visit to be enjoyable, hope for a pain-free night, or even hope for a peaceful passing is essential in order to maintain some sanity for the sake of your child. *Life's Toughest Moments* is a priceless companion to anyone confronted with the difficult choices no parent should ever have to make."—Aubrey Zimney

Aubrey Zimney, mother of Anna, and co-founder of *A Common Bond*, a non-profit foundation established by former ICU parents, which assembles comforting care packages for parents of hospitalized terminally ill infants. For more information, visit [www.acommonbond.org](http://www.acommonbond.org).

"Honest, powerful, candid. I applaud the authors for their depth and insight concerning all aspects surrounding the loss of a child and its impact on the entire family. The authors have truly given parents a powerful gift during this difficult experience." Christina Beall-Sullivan, MSN, APRN, author of "Hi, My Name is Jack", a book for the healthy siblings of chronically ill or dying children.



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