



***When A Cure Is No Longer  
Possible for Your Child***  
**A Guide for Parents and Caregivers**

## Table of Contents

<b>Introduction</b> .....	2
<b>Talking To Your Child About Dying and Death</b> .....	3
<b>Your Other Children</b> .....	7
<b>Exploring Clinical Trials</b> .....	8
<b>Deciding Where End-of-Life Will Occur</b> .....	9
<b>Hospice</b> .....	9
<b>Bereavement Care</b> .....	9
<b>Physical Changes Associated with Natural End-of-Life</b> .....	10
<b>Your Child's Natural End-of-Life</b> .....	11
<b>What To Do When Your Child Dies</b> .....	11
<b>If Your Child Dies Away From Your Hometown</b> .....	11
<b>Planning Your Child's Service</b> .....	12
.....	15
<b>Costs</b> .....	16
<b>Spiritual Considerations</b> .....	17
<b>Organ And Tissue Donation</b> .....	17
<b>Understanding An Autopsy (Post-Mortem Examination)</b> .....	18
<b>Wisdom From Other Parents</b> .....	19
<b>Additional Resources</b> .....	20

## Introduction

Parents never want to think that the day will come when their child will no longer be with them. Yet, when a child is very ill, parents often think about what they will do or what they should be considering as their child becomes more ill. This booklet is designed as a guide to help you as you begin to think about what might happen next. It provides information that can help guide you as you begin to make plans and informed decisions when end-of-life may be near or at the time of your child's death. These plans and decisions are all very personal- there is no right or wrong decision. What matters most is that the choices that you make feel right to you.

Some beginning suggestions:

### **Take your time.**

There are very few reasons to rush through reading this booklet or to hurry when making plans or decisions.

### **Engage the support of your medical team.**

It is normal to feel like no one else understands the intensity of your thoughts and emotions right now. Share your thoughts, feelings and concerns with the social workers, psychologists, nurses, physicians, child life specialists, or clergy that have worked with you and your child during his or her illness.

Make time to care for yourself and your personal needs. It is not possible to always meet the needs of every family member, especially as your child becomes increasingly ill. Caring for yourself will recharge your energy and provide you with the comfort and strength needed to get through this difficult time.



### **Build a support network of friends and family.**

Share this guide with friends and family members so that they can provide better support to you and help you with tasks and decision making.

## Talking To Your Child About Dying and Death

Remember that as a parent you have guided your child throughout their life and illness, and it is normal for them to expect that you will guide them through their death as well. By talking to your child about dying and death you can:

- *Learn what they already know and do not know*
- *Address misconceptions*
- *Provide comfort and understanding by reducing their fears or worries*
- *Support positive beliefs and attitudes especially around perceptions of giving up*

Most children are aware of changes in their body and often have thought about what is happening with their illness with more maturity than you might expect. Talking openly and honestly with your child gives them the chance to share their feelings and ask questions which they may hide out of concern for upsetting you. Although this may feel very difficult right now, parents who have lost a child have shared that it was through these conversations that they and their child found the most comfort.

As always, remember that the members of your medical team including social workers, psychologists, nurses, physicians, child life specialists, and clergy are available to help you.

### Age-related Considerations

When discussing dying and death with your child, it is important to remember that children.

- Have a difficult time understanding abstract ideas. For example, using a word like sleep when talking about death can lead children to think they can wake up.
- Are usually most afraid about being separated from you.
- Often have questions about the pain associated with death and may think of death as being a punishment.
- Have concerns about what happens to their bodies and personal belongings after death.
- Are concerned that they may be forgotten.

Adolescents tend to have a more complex understanding of death and often focus on finding meaning and purpose in their remaining life and in their death. However, some adolescents resist the idea that they can die.

Regardless of your child's age or level of maturity, reassure them that you will always be there to comfort and care for them. Let them know that you and the medical team will do everything possible to keep them comfortable and assure them that they did nothing wrong. It is also important that you tell your child they will always be remembered.

### **Advice for starting the discussions with your child**

- *Talk to your child at a time when they are most likely to share their thoughts.*
- *Explore what your child knows or wants to know about their illness, prognosis, and care. Let your child know that you will always be truthful.*
- *Explain medical information using words that your child will understand.*
- *Be supportive of your child's emotional reactions.*
- *Reassure your child that you will listen and be supportive.*



### **More guidance to consider**

- *Be honest and open with your child. With so much changing around them, children need to know that you will stay the same and always be available.*
- *Children often respond best to words and conversations that they are familiar with. Try starting discussions with: "Do you remember when we talked about...", "Do you remember when I told you that I would always be...", "Today we learned that..."*

- *It is okay to tell your child when the treatments have stopped working. It can be helpful to balance the bad news with something they will find comforting. For example, if your child will be cared for at home, explain to them that they will not have to go to the hospital nearly as often, that there will be fewer needle sticks, and that the family will be able to spend more time with them.*
- *Answer your child's questions using short and simple responses. Try not to overwhelm them with information that they will not understand.*
- *Don't hide your tears or feelings. Your child may think they have to do the same.*
- *Listen and accept your child's feelings. A roller coaster of emotions may surface from denial to anger. Be there to listen and validate your child's concerns.*
- *Be sensitive to your child's wishes. Do not force a conversation that they are not ready to have. Let them know that you are ready to talk with them whenever they are ready.*
- *It can be consoling for both you and your child to discuss the care and treatments they will receive to give them comfort during their end-of-life. Parents often find relief in being able to fulfill their child's wishes at such a difficult time.*
- *Your child may want to talk about their personal belongings and whether they might like them saved in a special way or shared with others. Your child may also have thoughts and wishes about their funeral service. It is helpful to be open to these discussions, especially if your child has already been thinking about what will happen next. Talking about some of the unknowns can be comforting for your child.*

### **How you can help your child**

Your child will need additional love and support, and a sense of stability during the end stages of their life. The following are a few ways you can help:

- Allow your child time to enjoy being a child. Play their favorite games with them and engage them in activities you know they enjoy. Parents who have lost a child often wish that they spent less time worrying or researching treatment options and more time playing with their child.
- Some children benefit from also having someone outside of the family (a trusted friend or member of the health care team) to talk to. This helps your child to express concerns that may be hard for them to share with you.
- Recognize when your child may or may not want to talk about death. Listening is the greatest gift you can provide for your child.

- Help your child feel a sense of control and comfort as they begin to experience the physical changes that may occur before death. Transitioning to a state of dependence on others may cause your child anxiety. Your acceptance and demonstration of comfort with these changes can provide a sense of peace for your child as they occur.
- Try not to let your guilt or grief affect your parenting skills and behaviors. Your child will benefit from your consistency.
- Some children worry about how hard their death will be for their parents. Let your child know that you will be okay, that you will always love them, and that they will never be forgotten.
- What many children fear most about death is dying alone. Offer your child reassurance and comfort that you will remain with them. If possible, hold or touch your child while they are going through the dying process. It can also be helpful to give your child permission to die when that time naturally comes.



## Your Other Children



The progression of illness and the death of a child can also be a very difficult time for the child's brothers and sisters.

Make time to understand the worries and fears of surviving children. Being honest and open about your feelings will make it easier for them to grieve. Sharing grief as a family can be a meaningful experience for everyone involved and an important process for healing.

Your other children may experience changes in mood and behavior as their brother or sister becomes more ill. They may demonstrate their emotions by being extra well-behaved, rebelling, or withdrawing from the family. These changes and challenges often occur when they need your closeness and guidance the most. Remember to check in regularly with your other children to discuss how they are doing. Also, connect with school counselors, family and friends for help during this time as you may be feeling stretched thin with responsibilities or emotionally over extended.

Before your other children visit the hospital, thoroughly prepare them for what they will hear and see. The condition and appearance of your hospitalized child and any equipment being used should be described before the visit. Ask your social worker or child life specialist to help you with these discussions.



Allowing your other children to visit the hospital and attend or participate in the funeral helps them to feel included, helpful, and important. Including your other children in these activities will also help them to cope with their grief and can provide them with comfort.

Keep school administrators and teachers informed of changes in the health status of your hospitalized child. It can become difficult for your other children to stay focused in school as their brother or sister becomes increasingly ill. They may need extra time or assistance with assignments or special accommodations to make up for school days missed. There are excellent resources for siblings listed in the reference section.

## Exploring Clinical Trials

If you want to consider available clinical trials after learning that standard therapy cannot cure your child's disease, it is important to understand that treatment from clinical trials may not cure your child's illness. However, by participating in clinical trials, you will contribute to research that can benefit other children with your child's disease. Contact your child's doctor for help with this decision.

### Advice when considering clinical trials

- *There is no right or wrong choice in exploring clinical trials. Children participating in clinical trials will continue to receive quality end-of-life care.*
- *Some clinical trials require travel to a different city, state, or country. The increased distance from family, friends, and your home hospital may cause additional stress and burdens.*
- *If a clinical study is being considered, it may be helpful to include your child in the decision making process. The discussion points can include the potential for more needle sticks and procedures, more time away from home, or the potential for death to occur sooner.*
- *Most children do not know that the treatment they are receiving is for research. In most hospitals, health care professions including social workers, psychologists, and child life specialists can help you to talk with your child about the goals of care and clinical trial options.*



The website [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and the toll free number of the Office of Patient Recruitment at 1-800-411-1222 are two resources for clinical trials that are available to the general public and supported by the NIH.

## Deciding Where End-of-Life Will Occur

When the end of your child's life is near, you may be able to choose where your child will spend their final moments. Many families feel that being at home with their child as natural end-of-life nears is important. Please discuss this early with your child's doctor and health care team so that they can support you in making the best decision, selecting the best time, and planning ahead. Sometimes there is a window of health in which a child can be stable enough to be safely and comfortably transported home for their end-of-life. If this is not an option, doctors, nurses, social workers, pain and palliative care services, and spiritual ministry are available at most hospitals to help maintain the quality of life for your child.



## Hospice

Hospice services are provided by a team of professionals who specialize in caring for children as they near the end of their lives. Hospice care can be provided in the home or wherever the child is and can be stopped or started according to the child's needs. Some children receive hospice care at home but return to the hospital for medical care or for their end-of-life. Discuss your considerations and decisions for hospice and end-of-life with your child's doctor and medical team.

## Bereavement Care

Hospices and other organizations can offer bereavement counseling to help you and your family to anticipate and respond to the emotional, physical, spiritual, and social impact from the death of your child. Often, families begin to grieve and feel sad long in advance of a child's death. Your hospice teams and bereavement counselors can help you and your family to understand healthy, normal stages of bereavement and to recognize symptoms of depression or complicated grief.

## Physical Changes Associated with Natural End-of-Life

As the end-of-life approaches, your child may go through transitions that include physical changes. These changes and the timeline for these changes are unique to each child. Sometimes anticipating these changes can help to alleviate fears or concerns associated with the dying process. Here is a brief and general overview.

- **In the weeks to days prior to natural death, some children experience:**
  - *Reduced energy and increased sleepiness or a sudden surge of energy known as a rally*
  - *Lack of interest in eating and drinking or weight gain due to a buildup of fluid in the body*
  - *Decreased interest in usual activities or social interactions*
  
- **In the days to hours prior to natural death, some children experience:**
  - *Changes in temperature that sometimes includes cooler hands and feet or increased perspirations and clamminess*
  - *Different patches of skin color including a pale, gray, or bluish appearance*
  - *Breathing patterns which vary from shallow and rapid breathing to deep and slow breathing, or irregular breathing patterns*
  - *Noisy breathing with a gurgling or rattling sound*
  - *Blurred vision, glassy looking eyes, or droopy eyelids*

Please talk to your child's doctor and medical team to learn what changes to expect for your child, and to learn about the medications and support available to ensure that your child remains comfortable.

## Your Child's Natural End-of-Life

Many families find it helpful to clarify with their home hospice agency or health care team who they should call if their child's natural end-of-life occurs outside of a medical setting. For example, a family member is usually given the telephone number of a medical provider that they can call at any time. This medical provider will coordinate the arrival of the care team to support the family and to attend to practical needs at the time of death.

Many families find comfort in holding their child and remaining present with their child; these moments are cherished and honored without rush. Some families chose to read a poem together, pray, or sit together in silence or sing a lullaby to their child. This time is respected for families. Many care teams are able to create hand prints or hand molds as part of respectful legacy-making for families.

## What To Do When Your Child Dies

After your child dies, a medical professional will help you to gently wash your child's body, remove certain medical devices, place fresh dressings or diapers on as needed, and dress your child in a clean gown or personal clothing that you supply. Just as you provided physical care for your child in life, you are invited to participate, if you are comfortable, in these final cares for your child after death.

All efforts will be made to give you and your family time at your child's bedside. At the hospital, when your family is ready, your child's body will be taken to the hospital morgue. Your child's body will be kept at the morgue until the time of transfer to the funeral home of your choice. Many parents ask if they can see their child's body once it leaves the morgue. This is a common request and you should let the staff of the funeral home know of your wishes so arrangements can be made.

If you have specific rituals or traditions at the time of death or afterwards, please speak to the staff about these in advance. Your wishes will be respected whenever possible.

Professionally trained chaplains (non-denominational clerics) are available to provide emotional and spiritual support to your family at this time. If desired, the chaplain can provide support with helping you to make decisions and can also be a liaison to provide specific religious, denominational, and cultural resources.

## If Your Child Dies Away From Your Hometown

If your child dies at a hospital away from your hometown and you wish to return your child's body to your hometown, planning should begin as early as possible. Local and international laws regulate the transportation of human remains. Each state and country has different requirements. A great resource to help you is a funeral director either in your hometown or locally where your child died. A funeral director can also advise you about the cost and process of transporting your child's body or cremated remains to another state or country.

## Planning Your Child's Service

- A funeral is the service that occurs just before the child's burial or cremation.
- A memorial service is a gathering to remember or celebrate the child's life. A memorial can take place at any time after death with or without the body or ashes, and can occur in more than one location and with different groups of people.

The idea of planning your child's funeral or memorial service can be a difficult and overwhelming task. Be gentle with yourself. Ask for help from family members, close friends, religious and spiritual leaders.

If you do not want a service based on a religion, spirituality, or cultural tradition your family members, close friends, and the director of the funeral home can help you to design a service that is most meaningful for you and your family.

If you would like a service based on a religion, spirituality, culture, or tradition, contact the leadership of your religious community and the funeral director for assistance.

In planning a service, you will want to consider the following:

- **Selecting the date:** *If possible, consider dates that accommodate out-of-town family and friends and dates that have significant meaning to your family.*
- **Choosing a location:** *A service can be held almost anywhere that is meaningful to your family, including a religious setting, a funeral home, a home, a park, at the cemetery, or other special place. Many of these locations need to be reserved, so advanced planning should be considered.*
- **Appointing a facilitator:** *The person you chose to lead the service can be a religious or spiritual leader, someone from the funeral home, a member of your family, or a close family friend.*
- **Creating a theme:** *Regardless of the setting of your child's service, many things can be done to provide special meaning. Think about your child's life, your family, and what was and is important to you, such as:*

- ❖ *Favorite stories and poetry*
- ❖ *Photographs, videos, slide shows, collages*
- ❖ *Toys, blankets, clothing Trophies, awards, mementos*
- ❖ *Music, art, dance*



## **Obituaries**

- *You will be given the opportunity to place an obituary for your child in one or more newspapers. This is not necessary, but an obituary can provide another way to remember your child and to provide important information to others.*
- *You may place an obituary in as many newspapers as you wish, keeping in mind that each one will charge a different fee. Pictures can be added, but will tend to increase the cost.*
- *You may write your child's obituary, or ask the funeral director or others to write it.*
- *Often, people will want to know how they can help you at this time. By clearly stating your wishes (which may include flowers or donations in your child's name to a fund or a charity), you can allow others to help you and to remember your child in a meaningful way.*

## **Choosing a funeral home**

A funeral home, also called a mortuary can be on the grounds of a cemetery or freestanding.

### **Considerations when choosing a funeral home include its:**

- *Prior experience*
- *Location*
- *Religious affiliation*
- *Sensitivity to your needs*

Social workers from the hospital or hospice can assist your family in contacting the appropriate funeral home to meet your needs.

## **Burial**

Burial can take place in a casket or in an urn (when cremation has been chosen). A standard burial plot is eight to ten feet in length. For babies and young children (usually under age three) the plot size is four feet. The children's section of a cemetery usually only has the smaller plot size. If you think you may want to be buried near your child in the future, it is important to remember that an adult cannot be buried in the children's section of the cemetery. A casket can also be placed in a cubicle called a crypt in an above ground structure called a mausoleum.

### **Considerations:**

- *You and your family will have a place of your own to visit.*
- *Burial allows for future options.*
- *A burial site can be changed, or the casket can be moved (in accordance with local laws and regulations).*

## **Cremation**

Cremation is a process by which the body is reduced to ashes by intense heat. The remains are then placed in a container, which can either be purchased or made. If you choose cremation, your child's remains can be:

- *Placed in a cubicle in an above-ground structure called a niche.*
- *Buried in a cemetery in a special area for cremated remains or placed near the burial plot of a relative.*
- *Kept at home or distributed among family members.*
- *Scattered in a place which is special to the child and family. Keep in mind that there are laws designating where remains can be scattered.*
- *Placed into jewelry.*

### **Considerations:**

- *Cremation does not prevent your family from having a viewing or funeral.*
- *You may be able to have some of your child's special possessions cremated with them such as a favorite blanket, stuffed animal, or toy.*
- *Some crematories allow family members to be present at the time of cremation. If this is your preference, ask in advance.*
- *If you are away from home and prefer cremation, it is less expensive to have the cremation performed locally rather than transporting your child's body.*
- *If you choose cremation, decisions regarding a final placement do not need to be made immediately.*

## Choosing a cemetery, memorial park, or garden

- *A cemetery generally has both raised and flat headstones.*
- *A memorial park or memorial garden usually has flat headstones.*



### Considerations:

- *Is there a cemetery where multiple generations of your family have been buried?*
- *How long has the cemetery or memorial park been in that location?*
- *Is there a religious affiliation?*
- *Who owns the grounds?*
- *What is the future maintenance plan for the cemetery once it becomes full?*
- *Is there a special section for babies and children?*
- *Are there special rates for a child's or baby's burial?*
- *Is one of the parents an honorably discharged Veteran? See additional details on page 16.*



- *Is there a mortuary or chapel on the grounds?*
- *How strict or lenient are rules regarding ornaments at the grave site (Do they allow flowers, wreaths, holiday decorations, balloons, etc.?)*
- *Decisions regarding a headstone can be made at a later date, but be sure to get some general information about headstones in advance.*

## Costs

It is important to remember that the love you have for your child is not reflected in how much money you spend on the funeral. Choose what is meaningful to you and your family and what is within your budget.

Funeral homes are privately owned, operate individually, and have different guidelines and costs. Some of them may have compassionate rates for discounted services and items and it is important to inquire if these are available for you. The funeral home may offer free or reduced rates in the case of a child's death. Be sure to obtain all agreements for services and cost in a written contract in advance of the funeral home providing any services.

It is also important to mention if your child was receiving any support from the Department of Social Services or Social Security. County and state agencies may have resources that can help cover some of the costs involved, as can some insurance plans.

### Cost Considerations:

- **Cremation:** Costs will depend upon the child's age, container chosen and services requested
- **Burial:** There will be separate costs for the services, casket, vault, burial site, headstone, and the opening and closing of the grave.

### Other costs can include:

- *Preparing and transporting your child's body*
- *Obtaining death certificates (you may need several originals and copies)*
- *Registering the death with the Vital Statistics Office*
- *Placing an obituary*
- *Use of the funeral home*
- *Funeral home supervising arrangements*
- *Personal choices such as balloons or dove releases*
- *Clergy*
- *Music*
- *Flowers*
- *Food and beverages*
- *Memorial book*
- *Thank you notes*



## Financial resources:

The director of the funeral home can assist with filing paperwork if applicable to your situation.

## Possible Payment Sources:

- **Medicaid:** *If your child has been a Medicaid recipient, contact the county Department of Human Services where the child resided.*
- **Veterans' Benefits:** *If a parent has served in the military, there may be financial assistance available. This can include free burial in a veteran's cemetery.*

## Spiritual Considerations

The way each person experiences death and grief will vary. The spiritual aspects of experiencing death and grief are individual to each person and will be framed in the context of one's spiritual preferences and practices. For some, religious and spiritual support may be absolutely vital to the experience of the death of a child and the grieving process. Some find that death and grief affects their ability to worship, pray or otherwise be engaged in their faith. Others may find themselves drawn closer to their faith and their faith community. Please know that these feelings are normal.

Your local community will likely have a number of resources through which you can find emotional, spiritual and religious support. You may seek out a community of faith, a spiritual leader or counselor, a support group, or a trusted friend or family member. There are many books and workbooks, several with a spiritual focus, which may help you through the grief process. You do not have to bear your loss and grief alone. Please seek support and guidance even though it may take great effort and courage to ask for help.

## Organ And Tissue Donation

The NIH Clinical Center is committed to protecting your rights to have the option of organ and tissue donation at the time of your child's death. The Clinical Center works with the Washington Regional Transplant Community in evaluating potential organ and tissue donors. If the Washington Regional Transplant Coordinator determines that donation is medically possible, they will contact you to explain your options. The Washington Regional Transplant Community ([www.beadonor.org](http://www.beadonor.org)) may be reached by telephone at 703-641-0100 or email at [contactwrtc@wrtc.org](mailto:contactwrtc@wrtc.org).

- *While many religions approve of organ and tissue donation, other religions or cultures do not consider organ donation an acceptable practice. This is a personal choice to be made by each individual family.*
- *An open-casket funeral is possible for organ and tissue donors. There is no cost to the donor's family for organ and tissue donation.*

## Understanding An Autopsy (Post-Mortem Examination)

Your child's doctors may ask your family for permission to perform an autopsy, which is also known as a post-mortem examination.

As a parent, you may ask why an autopsy is needed since you know why your child died. An autopsy is a procedure where a specially trained physician, a pathologist, will carefully examine your child's body to answer questions that you or the doctors may have about your child's condition or cause of death. Autopsies are often performed to provide information that could potentially help save the lives of others with similar conditions in the future. An autopsy, and the information possibly gained, has helped some parents answer remaining questions about their child's condition and the final cause of death, and to find meaning in their child's death.

Research has shown that parents who consented to an autopsy did not regret their decision. Many wanted to know if the autopsy findings could potentially help other children or help the medical team learn more about their child's illness. Some parents request to discuss the results with their medical team, while others prefer not to receive the autopsy results.

Autopsy Considerations:

- *It can be very difficult to face this decision during a time of loss and grief. Many families find it helpful before their child dies to discuss whether an autopsy might bring them comfort or be something that the family and their child might prefer.*
- *You can choose a limited autopsy or a full autopsy. In a limited autopsy, the pathologist will focus only on a specific part of the body or body system, for example, a child's tumor.*
- *The doctors might ask for your permission to retain tissues or organs for current or future studies. Doctors will also honor your requests for the treatment of your child's body. Please be sure to discuss these issues with your child's care team and the doctor who talks to you about the autopsy, and write your requests on the autopsy consent form.*
- *Your child's primary physician will receive a copy of the autopsy report six to eight weeks after the procedure. When you are ready, ask your doctor to review the report with you.*
- *An autopsy is generally performed soon after a child's death and generally takes no longer than a few hours. Therefore, the autopsy should not delay final arrangements including a funeral.*
- *If your child's death occurs outside of your child's medical center, please note that not all facilities are able to perform autopsies. Talk to your child's physician about your wishes. Parents can also request that the tissue or sample be donated to research at the time of death. Many parents and families find comfort in knowing that their child's disease is being used to develop better treatments.*

## Wisdom From Other Parents

- *While you are with your child when they are dying, you cannot tell them you love them enough. Let them know it is okay for them to go and that you will both be okay. Tell them that you will miss them and that you will remember them always.*
- *If you can safely hold your child without causing pain or harm, do so as much as you can. If you can lie in the bed with them and cuddle them, it may bring you and your child comfort.*
- *When your child dies, you may feel numb for quite a while. Don't try to make major decisions during this time without the help of trusted family and friends. Remember that you have to take care of yourself before you can really help anyone else. Your grief will be different from the grief of your spouse or significant other and your other children. Make sure you listen to each other and respect each other's grief process.*
- *Your family and friends will try very hard to say and do things for you to try and help. Some may not be able to find any words to express themselves. They all mean well, but may end up saying and doing things that might not feel right or appropriate to you. Don't use your energy to argue with them, just know that they are trying. Take each day as it comes, and handle what you can. Something you see or hear, such as a song on the radio, may cause emotions that are overwhelming. That is okay. Allow yourself a safe space to cry or do whatever you have to do to get past the moment.*
- *As time goes on, and healing begins, you will realize that you are not just existing anymore, but are living again, slowly, in small measurable ways. You can honor your child's memory in any way you feel comfortable. They will always live in your hearts. You are not alone. Many parents have lost children before you, and many others will come behind you. There are groups you can join for bereaved families when the time is right for you. The wisdom from other parents is invaluable. You will find that they may help you tremendously, and you may be surprised to know you are also helping them.*
- *At some point you might even want to visit the hospital where your child was treated. For some, this is very helpful. Many parents also find it harder than anticipated to return to a place that was so meaningful during their child's illness and death.*



## Additional Resources

### Books on Grief

Anderson M (author). Sacred Dying. Creating Rituals for Embracing the End of Life. Da Capo Press, 2003. IS N 1569244340.

Callanan M and Kelley P (authors). Final Gifts. Understanding the Special Awareness, Needs, and Communications of the Dying. Simon & Schuster, 2012. ISBN 1451667256.

Didion J (author). The Year of Magical Thinking. Vintage, 2007. ISBN 1400078431.

Goldman L (author). Great answers to difficult questions about death. What children need to know. Jessica Kingsley Publishers, 2009. ISBN 1849058056.

Redfern S and Gilbert SK (authors). The Grieving Garden. Living with the Death of a Child. Hampton Roads Publishing, 2008. ISBN 1571745811.

### Children's Books

Buscaglia L (author), Buscaglia L (illustrator). The fall of Freddie the leaf: a story of life for all ages. Slack Incorporated, 1982. ISBN 0943432898.

Durant A (author), Gliori D (illustrator). Always and forever. Picture Corgi, 2013. ISBN 0552567655.

Filigenzi (author), Bersani S (illustrator). Let my colors out. American Cancer Society, 2009. ISBN 1604430117.

Hanson W (author), Hanson W (illustrator). The next place. Waldman House Press, 2002. ISBN 0931674328.

McVicker E (author), Hersh N. Butterfly kisses and wishes on wings. McVicker & Hersh, LL , 2015. ISBN 0578159937.

Mellonie B (author), Ingpen R (illustrator). Lifetimes: the beautiful way to explain death to children. Bantam, 1983. ISBN 0553344021.

Mills J (author), Pillo (illustrator). Gentle willow: a story for children about dying. Magination Press, 2004. ISBN 1591470714.

Oliver S (author), Oliver E and L (illustrator). A fish named Ed. Fideli Publishing, 2008. ISBN 1604140496.

Olivieri L (author), Elder K (illustrator). Where are you? A child's book about loss. Lulu, 2007. ISBN 1435700910.

Raschka (Children's Hospice International- author), Raschka (illustrator). The purple balloon. Schwartz & Wade, 2012. ISBN 0375841466.

Stickney D (author), Nordstrom RH (illustrator). Water bugs and dragonflies: explaining death to young children. Pilgrim Press, 2009. ISBN 0829818308.

Varley S (author). Badger's parting gifts. Harper Collins, 1992. IS N 0688115187. Wilhelm H (author). I'll always love you. Dragonfly Books, 1998. ISBN 0517572656.

### **Resources to help you talk to your child about end of life**

My Wishes	<a href="http://www.agingwithdignity.org.shop/product-details/pediatric-my-wishes">www.agingwithdignity.org.shop/product-details/pediatric-my-wishes</a>
The Conversation Project	<a href="http://www.theconversationproject.org">www.theconversationproject.org</a>
Voicing My Choices	<a href="http://www.agingwithdignity.org.shop/product-details/voicing-my-choices">www.agingwithdignity.org.shop/product-details/voicing-my-choices</a>

### **Bereavement Services**

Resolve Through Sharing	<a href="http://www.bereavementservices.org">www.bereavementservices.org</a>
The Compassionate Friends	<a href="http://www.compassionatefriends.org">www.compassionatefriends.org</a>
The Dougy Center	<a href="http://www.dougy.org">www.dougy.org</a>

### **Hospice Information**

Hospice. [www.hospicenet.org](http://www.hospicenet.org)

A collection of resources and advice for patients and families facing life threatening illness including articles on death and dying, care, and other end of life issues.

National Hospice and Palliative Care Organization. [www.caringinfo.org](http://www.caringinfo.org):

Free resources to help people make decisions about end-of-life care and services before a crisis

**For more information about this publication, contact:**

Lori Wiener, PhD  
Co-Director, Behavioral Health Core  
Head, Psychosocial Support and Research Program  
Pediatric Oncology Branch, Center for Cancer Research  
National Institutes of Health  
9000 Rockville Pike, Bethesda, Maryland 20892  
Phone: 301-451-9148  
Email: [wienel@mail.nih.gov](mailto:wienel@mail.nih.gov)

National Institutes of Health Publication Number: 17-CC-8034