

14

END-OF-LIFE CARE



Awareness and discussion of end-of-life issues are important aspects of care for any serious illness and helps improve quality of life. Talk to your child's healthcare team about treatment goals and any concerns you have related to prognosis, treatment outcomes and end-of-life care.

Although treatments for children with cancer have improved, some children do die of their disease or complications related to treatment. Children nearing the end of life have specific needs and concerns that their parents will have to consider. Thinking about your child's potential future need for medical care and discussing end-of-life preferences may be painful, difficult or uncomfortable. You may worry that discussing end of life undermines hope for improvement and recovery. However, end-of-life planning is about taking steps to live as well as possible every day. Turn to the members of your child's healthcare team as well as the members of the hospice team (see **Hospice** on page 3), for support and guidance for you, your child and your family.

Choosing to Stop Treatment. At some point, you may need to consider stopping treatment or stopping aggressive treatment for your child's disease. This can be a difficult choice to make. It may be time to think about stopping treatment when:

- Your child has exhausted multiple treatment options without improvement or with continued disease progression.
- Your child's quality of life has declined drastically without hope for improvement.
- Your child is too sick to continue treatment safely.
- Your child no longer wants to seek treatment and understands the implications of this choice.

You and your co-parent will be making decisions regarding your child's future care. People who can be helpful and may be included in discussions include:

- Your child
- Members of the healthcare team
- Other close family members
- A spiritual leader

End of life is a challenging and emotional time for everyone who loves your child. Well-meaning family members or friends may let you know that they disagree with your decisions. However, ultimately, these decisions rest with you, your co-parent and your child. Your child's wishes are important. Respect them. If a child wants to participate in the decision-making process, they should be included in discussions about their ongoing care.

If you, your co-parent and/or child disagree about ongoing care, work with members of the healthcare team, including a child-life specialist and a mental health professional, to work through disagreements so everyone can be on the same page.

Discussing Death With Children. Many factors influence a child’s understanding of death and dying, including:

- Age and maturity
- Experiences with death, such as the death of a grandparent
- Depictions or descriptions of death in books, movies and television
- Spiritual, religious or cultural beliefs

You may find it helpful to ask your child what they understand about death so you can correct any misunderstandings. Consider the following strategies for discussing death with your child:

- Be direct. It may be uncomfortable to use the word “death” or “die,” but phrases such as “pass away” or “go to sleep” can be misleading and confusing, especially for younger children. Connecting sleep with death can also cause a child to be afraid of going to sleep.
- Answer questions. Your child may ask very direct questions about death. Do not dismiss or avoid answering these questions. Your child may specifically ask if they are going to die. Your gut reaction may be to say “No,” but your child deserves an honest answer, especially near the end of life. Your child may ask questions that you don’t know how to answer. It is okay to tell your child that you don’t know the answer. You can reach out to the child-life specialist or other members of your child’s healthcare and/or hospice team for help with answering difficult questions.
- Provide opportunities for questions. Let your child know that they can always come to you with questions. Children may be afraid to ask you questions if they think the questions will upset you. Your child may be afraid of dying alone or of being in pain. If your child can express specific fears, you will be able to address these, offer comfort and reassurance and correct any misunderstandings.
- Be consistent. Talk to your co-parent and other important adults in your child’s life. Your child is likely to ask different people the same questions about death. As much as possible, your answers and the information others share with your child should be similar to avoid confusion. Share your family’s beliefs about death and/or life after death with the members of both the healthcare and hospice teams for consistency.
- Let your child guide the conversation. Just like adults, children cope in different ways. It is okay if your child prefers not to talk about death at length, as long as they don’t have any misunderstandings about the dying process that cause anxiety or isn’t avoiding talking about death because of other concerns, such as upsetting you.
- Ask for help. Talk to the child-life specialist or members of your child’s healthcare and hospice teams for guidance. They can help facilitate a conversation about death with you, your co-parent and your child. Older children and teenagers may want to speak to members of the healthcare and/or hospice team alone. If you are part of a religious community, you can also reach out to religious leaders to help with discussions.
- Remember siblings. If your child has siblings, remember to talk with them as well. The strategies outlined above can also be useful when speaking to your other children. Siblings may have feelings of guilt. Reassure siblings that they did nothing wrong to cause their sibling’s illness and/or death. Allow your children to spend quality time with their ill sibling in the time leading up to death. You may wish to shield younger siblings from the emotional pain of seeing a sibling die, but the time spent together and the chance to say goodbye are very important parts of coping.

TIP:

Children deserve to know if they are nearing death. This knowledge allows children to ask questions, make requests, say goodbye and prepare for death in a way that is comfortable and meaningful for them just as it would be for adults.

Hospice. Hospice embodies a philosophy that delivers compassionate care to people, including children, who are approaching the end of their lives and provides emotional and physical support to them and their loved ones. Hospice offers medical care that focuses on maintaining and improving quality of life for someone whose disease or condition is unlikely to be cured. An interdisciplinary hospice team provides medical care, pain control and emotional and spiritual support that is tailored to the individual needs of each patient and their family. The hospice philosophy also encompasses the belief that every person has the right to die with dignity and without pain, and that families should receive the help and support needed to participate in the process.

By providing care that makes your child as comfortable as possible and improves quality of life, hospice care can free up emotional and mental space so that your child can live out their days in ways that are meaningful.

Most hospice programs enable the patient to stay at home. However, hospice care can also be provided at a freestanding hospice care facility or in a hospital setting. Usually, the hospice team is made up of hospice doctors, nurses, social workers, home health aides, volunteers, and chaplains or other pastoral counselors.

Some of the services provided by hospice include:

- Pain management
- Emotional and spiritual support
- Family coaching and sibling support
- Provision of drugs and medical supplies for comfort care
- Home health aide placement and supervision

Your child may be eligible for hospice:

- If they have a life expectancy of 6 months or less
- If they stop receiving curative treatment

TIP:

Before leaving the hospital, if you choose to do so, get a referral to a hospice agency and schedule the initial visit.

Questions to Ask Members of the Hospice Team

- What should I expect during this time?
- Can I receive all care instructions in writing?
- Whom can I call with general questions?
- Whom can I call after hours in an emergency situation?
- What signs and/or symptoms require a call to the hospice team?
- What medical equipment or supplies will be provided?
- What is the schedule for visits from members of the hospice team?
- What are the signs and/or symptoms that mean death is near?
- What do I need to do when my child dies?



Contact the following organizations for more information about hospice:

- National Hospice and Palliative Care Organization: www.nhpc.org
- Hospice Foundation of America: www.hospicefoundation.org
- Children's Hospice International: www.chionline.org

You can also ask a member of the healthcare team for a referral to hospice.

In-Home Hospice Care and Parent Responsibilities. If your child receives in-home hospice care, members of the hospice team will help you provide care for your child. With in-home care, a healthcare professional will not be present at all times, but a nurse will visit your child on a regular schedule. The hospice team will teach you how to:

- Administer medications
- Care for an intravenous (IV) line or a central line

- Use any necessary medical devices or equipment
- Provide nutrition
- Make your child comfortable
- Assist with bathing and skin and mouth care

Your child should not be left alone as their life draws to a close. Work with your co-parent, family members, friends and the hospice team to coordinate round-the-clock care.

You will likely want to spend every possible minute with your child. As much as possible, try to take time for yourself to rest and recuperate so you can provide the best care for your child. Lean on family members and friends during this difficult time.

Pain Management Near the End of Life. As the end of life approaches, your child may be in pain. The hospice team will help with pain management to make your child more comfortable. In a hospice setting, pain management often involves strong medications. These medications may be given orally or intravenously. A member of the hospice team will teach you how to administer them. If your child's pain is not controlled by the prescribed medication or dosage, let the hospice team know as soon as possible so that the prescribing doctor or member of the healthcare team can make the necessary adjustments. Pain is more difficult to control if it is allowed to build up. Other pain management methods, such as massage, may also be used.

Care Decisions at the End of Life. Care at the end of life is intended to bring comfort and improve quality of life for your child. Take time to think about the priorities and goals for your child's care. Include older children and teenagers in the discussion. You may want to consider such questions as:

- What are the important activities of daily living that will contribute to your child's quality of life (for example, being able to speak with family members and friends, play or enjoy food)?
- What would make your child more comfortable as the end of life approaches?
- What religious or spiritual considerations matter to you and your child (for example, rituals)?

Discuss the answers to questions like these with members of the hospice and healthcare teams. The team can then suggest types of comfort care and medical and practical interventions that can satisfy the priorities and achieve the goals you have set for your child's care.

Advance Care Planning for Children. Legal adults can communicate their wishes and preferences for medical care in a legal document called an "advance directive" or "living will," created through a process called "advance care planning." Children can also participate in advance care planning. Although children cannot create legal documents, they can express their wishes and preferences for medical care through a written document and by speaking to their parents and members of their healthcare team.



The following resources can guide these discussions with your child:

- *My Wishes* is a booklet written in everyday language (available for purchase at <https://fivewishes.org/shop/order/product/pediatric-my-wishes>) that helps children express how they want to be cared for in case they become seriously ill. You can view a sample of the *My Wishes* document at the link.
- *Voicing My Choices* is a discussion guide (available for purchase at <https://fivewishes.org/shop/order/product/voicing-my-choices>) that empowers young people who are struggling with a serious illness to communicate with family members, friends and caregivers about the type of care that they want now and in the future.

For more information on advance directives, visit www.LLS.org/booklets to view ***Advance Care Planning***.

As individual maturity allows, children and teenagers deserve an opportunity to prepare for their end of life. This provides your child with respect, dignity and control in the most difficult of situations.

Physician Orders for Life-Sustaining Treatment (POLST) Paradigm.

“Physician Orders for Life-Sustaining Treatment (POLST)” are medical orders for a person who has a progressive serious illness or who is nearing the end of life. These orders are sometimes referred to as “Medical Orders for Life-Sustaining Treatment (MOLST)” or by other names, depending on the state you live in. A POLST form is completed by the doctor with input from the patient or, in the case of minor children, the child’s parents or legal guardians. **It specifies the preferred treatment(s)/intervention(s) that the patient will receive during a medical emergency.** Pain management and comfort care will always be a priority. As your child nears the end of life, you may choose to decline other medical interventions based on preferences and priorities for your child’s end-of-life care. The POLST forms and laws differ by state and not all states have a standardized form yet. Visit <https://polst.org/programs-in-your-state> for more information.

A POLST form may address decisions about:

- Attempting cardiopulmonary resuscitation (CPR)
 - Cardiopulmonary resuscitation is an emergency procedure that is used when the heart stops beating or breathing stops. It attempts to restart the heart or breathing. Cardiopulmonary resuscitation combines chest compressions and artificial ventilation and may include electric shock and medications.
- Implementing intubation and mechanical ventilation
 - Intubation is the placement of a tube that is passed either through the nose or through the mouth to help with breathing. The patient will likely be sedated.
- Providing artificial nutrition and hydration (tube/intravenous feeding)
- Use of antibiotics
- Pain management
- Transfer to an emergency room or the hospital

If treatment options have been exhausted or when no treatment is available for an underlying disease, illness or injury, these medical interventions may prolong life, but they may not lead to a meaningful recovery. Some medical interventions also carry risks that can decrease quality of life. For these reasons, some people choose to forgo these medical interventions when the end of life is near. Discuss medical interventions, and how these interventions will affect your child, with members of the healthcare and hospice teams.

Orders on a POLST form can always be cancelled or updated.

Other orders used in end-of-life care include “do not resuscitate (DNR)” and “allow natural death (AND)” orders which instruct healthcare professionals that CPR is not to be attempted. These may be separate orders or they may be included on a POLST form.

Making the Most of the Time Left With Your Child. Hospice care is typically provided in a comfortable, private space whether at home or in a medical facility. This means that your child will have the opportunity to spend more quality time with close family members and friends. During this time your child may want to:

- See or speak to family members and friends
- Share fond memories and look at photographs or home videos
- Watch favorite films or listen to favorite music

TIP:

A POLST form is only created for patients who are nearing the end of life. A POLST form helps patients and families to meet their goals for end-of-life care. Even if a family chooses to decline specific medical interventions, comfort care will always be provided.

- Write messages to family members and friends
- Give away possessions such as favorite toys or books

Even if your child hasn't developed language skills, physical touch, such as holding your child or rubbing their back, can be a great source of comfort for you and your child. Other ways you can help your child include:

- Letting your child play in safe, age-appropriate ways. Even terminally ill children want to play and benefit from doing so.
- Continuing to set limits within your normal parenting style. Without limits or structure, your child may feel more out of control.
- Allowing your child to express their feelings whether those feelings are anger, fear, sadness or acceptance

The Dying Process. The hospice team will help you prepare and teach you what to expect. For in-home hospice care, you will also need to know what to do and whom to contact when your child dies. The hospice team will provide you with instructions.

As your child's life draws to its close, there are things you can do to make them more comfortable. For example, you can:

- Talk, read or sing to your child even if it seems as though they can't hear you.
- Try to fulfill any requests (eg, providing favorite music that your child wants to listen to or pictures they want to look at).
- Keep a favorite stuffed animal, toy or night-light nearby.
- Hold your child or their hand to provide a comforting physical touch.
- Use pillows or adjust the bed to keep your child's head elevated so it is easier for them to breathe and swallow.
- Wash your child's face and hands gently with a warm washcloth.
- Keep your child's mouth, lips and nostrils moisturized and lubricated to prevent cracking and dryness.
- Care for your child's skin by keeping it clean, dry and moisturized.
- Help your child turn or change positions on the bed to prevent sores and cramps.
- Clear debris around oxygen tubes.
- Put a disposable pad on the bed to help with cleaning up waste.

In the last days or weeks leading up to death, you may notice the following changes in your child's condition:

- Changes in sleeping patterns
- Increased weakness
- Decreased appetite
- Changes in cognitive function (eg, confusion, hallucinations or vivid dreams)

Your child may experience a wide range of feelings and sometimes conflicting emotions. They may wish to see and speak with family members or friends. Or, they may become withdrawn or agitated.

Death can bring fear and suffering, but remember, it can be gentle too. As life draws to a close, your child may welcome death and the peace it can bring with it. When you sense the time is right, you may be able to help your child. Perhaps that means finding a way to let your child know that the struggle is almost over, that they can rest now and just "let go." To you, this may feel almost like giving your child "permission" to die.

Make sure that your child knows that they won't be alone. Trust your feelings—you will know what to do. Tell your child how very much they are loved. Help your child to understand that people will always care about them. Knowing that people dearly love them, no matter what, may give your child some peace.

As death draws closer, there may be:

- A loss of bladder or bowel control
- Drifting in and out of different levels of awareness or consciousness
- Changes in breathing, faster or slower, or a different rhythm
- A bluish tint to the skin, starting with the hands and feet

Bereavement. Losing a child is possibly the most difficult thing a parent can experience. Grief can affect each person emotionally, physically, cognitively and behaviorally. These aspects of grief manifest themselves in many ways.

For instance:

- Emotional effects include feelings of sadness, anger, guilt, self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief and numbness.
- Physical effects include the sensations of hollowness of the stomach, tightness of the chest, tightness of the throat, oversensitivity to noise, breathlessness and shortness of breath, weakness of the muscles, lack of energy and dry mouth.
- Cognitive effects encompass disbelief, confusion, preoccupation, a sense of presence, hallucinations and a lack of focus.
- Behavioral effects manifest as sleep disturbances, appetite disturbances, absent-mindedness, social withdrawal, dreams about deceased loved ones, searching and calling out, sighing, restlessness, crying, visiting places or carrying objects and treasuring them.

All these manifestations of grief are normal in the immediate days or weeks following the passing of a child. Grief is not bound by time but, eventually, the intensity of normal grieving does become more manageable.

Different Ways of Expressing Grief. Many people express grief in an outward way; for example, crying, a lack of energy or trouble sleeping. Others, on the surface, may not seem to be grieving. Instead, these people process grief internally. Their grief may go unrecognized and unacknowledged. Be aware that grief is personal and specific to the person. Try not to make judgments about how you, your co-parent or others process the loss of your child. The manner and timing of your approach to your loss and how you work through your grief depends on you as an individual.

Siblings and Grief. Siblings are sometimes called the “forgotten grievers.” After the death of a child, the parents are likely to be the main focus of attention; however, siblings need comfort and guidance too during this time. Children may not be able to fully comprehend the nature of death until they’re about 10 years old. However, children are capable of sensing separation and experiencing grief at a very young age. Children’s grief is different than that of adults. The ways in which children experience and express grief depends on their developmental level. Here are some things to keep in mind:

- Children’s grief is cyclical. Children will grieve within the confines of their developmental stage and then, when they are more developmentally advanced, they may revisit their loss and grieve for their loved one all over again.
- Just like adults, children may feel a range of emotions including guilt, anger, anxiety, sadness and fear.
- Milestones may bring up grief years later. As children grow older, they may feel grief strongly around milestones such as birthdays or graduations that they aren’t able to share with their sibling.
- Younger children may only experience sadness for short periods. Children younger than 6 years may not understand that death is final. They may feel sad because you and others around them are sad, but soon they may want to play and return to normal activities. This does not mean that they did not love their sibling.
- Teenagers usually have a full understanding of death, but they likely do not have enough experience with death to have developed coping skills. They may not feel comfortable talking about their feelings. They may question their understanding of the world. Teenagers may seek comfort from friends instead of parents or other family members.

TIP:

Be kind and patient with yourself. Everyone expresses and processes loss differently. Do not feel pressured to grieve in a specific way. Allow yourself the time you need to feel your emotions and to heal.

Ways to Help Siblings Cope. You can help your children cope with the loss of a sibling by:

- Providing reassurance and affection for your children so that they feel loved and supported
- Allowing the siblings to choose whether or not to attend the funeral or memorial service. Prepare your children for what to expect. You may want to ask an adult your children trust to keep an eye on them during the service as you may be distracted, and your younger children may need comforting or even wish to leave early. Allow older children and teenagers to be involved in the service if they want to be.
- Allowing your children to talk about their sibling and ask questions even if it may be difficult for you to hear at times
- Trying to keep routines consistent, and continuing to set limits so that your children do not feel overwhelmed
- Asking the healthcare team or hospice team for a referral to a grief counselor or child psychologist if a child needs additional help coping

Ways to Remember Your Child. As time passes and your grief becomes more manageable, you may search for ways to remember the child you lost. There are many ways to do this. Some of the following ideas may help you and your family to honor your child's memory:

- Visit your child's resting place if they were buried, or visit a favorite place where you spent time with your child, such as a park.
- Frame an item of clothing, an accessory, or some other token that reminds you of your child.
- Create a scrapbook with some of your favorite photos, cards or letters.
- Plant a flower or tree in your child's memory.
- Invite friends and family members over on a special date to share fond memories of your child.
- Volunteer (in your child's memory) for an organization.

Honor your child in a way that is meaningful to you and in a way that brings you comfort. Encourage your co-parent, your child's siblings and other family members to do the same.

Seeking Support. Sometimes, a person may become stuck at some point in the grief journey or express grief in an unhealthy way. If you find yourself, your co-parent or children unable to return to daily life or find enjoyment seek the services of a grief counselor or professional therapist.



Organizations that provide bereavement support and resources include:

- The Compassionate Friends: www.compassionatefriends.org
- Bereaved Parents of the USA: <https://www.bereavedparentsusa.org/>

For counseling and bereavement support group referrals, speak with an LLS Information Specialist at **(800) 955-4572**.
