

## [Caring for a Terminally Ill Child: A Guide for Parents](#) [1]

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Despite the health care team's best efforts, it may not be possible to cure your child's cancer. But this does not mean it is untreatable. Children with [advanced cancer](#) [3] sometimes live for many months or even years. During this time, treatment focuses on controlling the cancer, when possible, and managing symptoms so a child can enjoy a high quality of life for as long as possible. Parents play a crucial role in helping a child continue to live a fulfilling and comfortable life and prepare for a peaceful and dignified death.

Talk openly and honestly with your child's doctor and health care team about your family's feelings, preferences, and concerns. Many team members have special skills, experience, and knowledge to support children with advanced cancer and their families.

### **Caring for your child's symptoms and side effects**

Special types of medical care are available to help with symptoms for children with advanced cancer.

- **Palliative care.** Doctors provide this treatment at any stage of the disease to relieve symptoms and side effects caused by cancer or its treatment. Palliative care helps a child with cancer live as comfortably as possible. It also addresses the psychological, social, and spiritual needs of the child and family.

Palliative care is not an alternative to cancer treatment. Children with cancer often receive treatment for the cancer and treatment to ease side effects at the same time. Palliative care is given as early as possible in the cancer treatment process, and it continues throughout the course of cancer. Learn more about [palliative care](#) [4].

- **Hospice care.** This form of palliative care is provided to patients who are expected to live six months or less. In the past hospice was only for children who were no longer receiving cancer treatment. However, many states now allow for hospice care and cancer treatment to be given at the same time for children who have limited time to live. Regardless, children can continue receiving palliative care while in hospice care. Hospice services are often focused on providing the support needed for care at home. But both palliative and hospice services may be provided in a hospital or in a private care facility.

Many families want their children to spend the majority of their remaining time in the comfort of their own home, surrounded by family, pets, and special belongings. Palliative care enables most children to remain at home for as long as possible. However, some children and families are reassured by the hospital environment and find comfort in the close relationships they develop with the hospital staff and other children. As a result, some families may choose to receive care at the hospital, rather than at home. Talk with your child's health care team about the setting that feels best to you, your child, and your family. Learn more about [hospice care](#) [5].

## **The importance of talking with your child**

Talking about death may be the most difficult step in caring for a child with advanced cancer. Below are a few things to consider when making this decision:

- How and when you talk with your child about the subject is a personal decision.
- This decision is also influenced by many factors, including the expected course of your child's cancer and your opinion about what information is appropriate to tell your child. If your child's cancer advances slowly, you may have more time to decide how to approach it. If your child's cancer develops more rapidly, you may choose to talk with your child immediately. You are the best judge of what and when to tell your child.
- Some parents believe they can protect their child by not telling them the truth. However, most children with advanced cancer already know or suspect that they are dying, based on watching the adults around them and the changes they experience inside their bodies.
- Be honest and open. Your child will feel less anxious if he or she knows what to expect. And talking about your child's death enables you both to have closure by sharing memories, expressing love, and saying good-bye.
- Allow your child to discuss his or her fears and questions. Knowing how your child views death will help you understand how to respond to these questions.

- A major factor influencing your child's understanding of death is his or her developmental level. For example, preschool-aged children are too young to understand the concept of death—particularly its permanence. School-aged children are just beginning to understand death as a final separation. Meanwhile, teenagers typically have an adult understanding of death, but it directly challenges their feelings of immortality and their growing need for independence.
- Your child's understanding of death is also influenced by cultural norms, your family's religious beliefs, and views seen on television or read in books.

## **How to talk with your child about death**

Talking about death and dying is always difficult. Ask social workers, nurses, child life psychologists, or other specialists for advice about how to talk about death with your child. The following tips may also be helpful:

- Look for signals that your child is ready to talk, such as asking questions or bringing up the subject of death. And look for signals that your child is done talking for the moment. These include changing the subject, looking away, fidgeting, or playing with toys.
- Look for "teachable moments"—everyday opportunities to talk about what your child is thinking and feeling. Teachable moments may include the death of a pet or the illness of a character in a book or a movie.
- Use simple, direct language that your child can understand. For example, use the words death and dying, rather than misleading or confusing terms such as “passing away” or “going to sleep.”
- Ask open-ended questions that give your child the chance to answer in his or her own way. For example, ask, "How did you feel when Grandma died?" Open-ended questions are better than "yes" or "no" questions, such as, "Were you sad when Grandma died?"
- Look for hidden meanings in your child's questions or comments. For example, your child may ask, "What do you think happened to Grandma after she died?" This may be your child's way of asking what will happen to him or her.
- Allow younger children to communicate through play or art. Your child may find it easier to talk about the feelings of a sick teddy bear or a child in a picture.

When discussing death, the following reassurances can be especially helpful for your child:

- Reassure your child that he or she will not be alone. It is important for children to know their parents will be with them when they die and that parental love and support will continue.
- Reassure your child that all pain and suffering goes away after death and never comes back.
- Remind your child of the special things he or she has done and the teachers, friends, nurses, and others who will always remember him or her.
- Discuss your family's religious or spiritual beliefs about death and what happens after death.
- Give your child "permission" to die, if you believe that will help. Many dying children feel guilty leaving their parents and worry about what will happen to their family without them.

## **How to meet your child's needs**

Although parents often feel powerless caring for a child with advanced cancer, you can take steps to help meet your child's psychosocial and physical needs. As your child's cancer progresses, the needs will change. Pay close attention to your child's behavior to adjust to these changing needs.

Here are some tips to help your child experience the fullness of childhood for as long as possible:

- Give your child time to play and engage in other age-appropriate activities, such as watching television, reading, or exploring the outdoors.
- Encourage your child to continue attending school, even if he or she cannot attend full time. If your child must miss school for a long time, ask the teacher to have the class write letters, draw pictures, or make videos.
- Encourage your child to maintain friendships and other meaningful relationships.

- Encourage your child to continue setting goals. Short-term goals, such as learning to read or taking a special trip, help children gain a sense of achievement and give meaning to their lives.
- Continue setting limits on your child's behavior and practicing normal parenting. Without limits, your child will feel overwhelmed and out of control.
- Advocate for your child to ensure that pain and other symptoms are quickly treated.

As your child's cancer progresses and death approaches, he or she will have additional needs. Consider taking these steps during that time:

- Give your child as much privacy and independence as possible.
- Encourage your child's end-of-life wishes. These may include giving away special belongings, writing letters to friends, or going on a special adventure. Learn about [organizations that help children fulfill their wishes before the end of life](#) [6].
- Give your child time to say good-bye to family, friends, teachers, and other special people. This can be done in person, with letters, or through a parent.
- Make caregivers and medical staff aware of your child's ongoing physical needs, especially the need for pain management.
- Talk about the physical symptoms and changes your child can expect as his or her cancer progresses. But avoid scaring him or her. Remind your child that the doctors and nurses will help make the symptoms better. That way, he or she can feel as good as possible. Knowing what to expect will ease anxiety and fear.

## **How to find support for yourself**

It is not natural for parents to outlive their children. Nothing can erase the anguish and distress that parents experience caring for a child with advanced cancer. The following suggestions may help you cope:

- Talk with your spouse, family members, or friends about your feelings and fears. It is normal to experience emotions such as anger, guilt, and frustration.

- Seek support from a professional grief counselor, or attend a [support group](#) [7] with other parents of children with advanced cancer.
- Take advantage of offers for help from family and friends to ease your physical and emotional exhaustion.
- Ask the medical staff to explain symptoms that occur close to death, such as skin and breathing changes. Knowing what to expect will help you feel more prepared.
- Make sure [advance directives](#) [8] and other such documents are in place before the need arises.
- Consider making funeral arrangements and other plans—such as deciding whether to have an autopsy—in advance. By planning ahead, you can spend more relaxed time with your child at the end of life and avoid making decisions in a crisis.
- Spend time with your child, and tell him or her how much you love him or her. Some parents, children, and other family members find it helpful to look through photo albums and share stories and memories of times spent together.

Learn more about [taking care of yourself as a caregiver](#) [9].

## More Information

[How a Child Understands Cancer](#) [10]

[Grieving the Loss of a Child](#) [11]

[Care Through the Final Days](#) [12]

## Additional Resources

Hospice Net: [Talking to Children About Death](#) [13] and [Children's Understanding of Death](#) [14]

[Children's Hospice & Palliative Care Coalition](#) [15]

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### Links

[1] <http://www.cancer.net/es/node/25280>

[2] <http://www.cancer.net/es/node/51>

- [3] <http://www.cancer.net/node/25113>
- [4] <http://www.cancer.net/node/31921>
- [5] <http://www.cancer.net/node/25281>
- [6] <http://www.cancer.net/node/24742>
- [7] <http://www.cancer.net/node/25383>
- [8] <http://www.cancer.net/node/25278>
- [9] <http://www.cancer.net/node/25031>
- [10] <http://www.cancer.net/node/25300>
- [11] <http://www.cancer.net/node/25288>
- [12] <http://www.cancer.net/node/25279>
- [13] <http://www.hospicenet.org/html/talking.html>
- [14] <http://www.hospicenet.org/html/understand.html>
- [15] <http://www.chpcc.org/>