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

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 06/2013

### **Key Messages:**

- If your child's cancer cannot be cured, the focus of treatment transitions to managing your child's symptoms in a comfortable setting.
- Your child's health care team can help you understand how your child's needs will change and how you can be supportive.
- It is important to talk with your child about death and dying, even though such conversations are extremely difficult; how and when you have these discussions is a personal decision.
- Seek support during this distressing time as you care for your child.

Despite the health care team's best efforts, it may not be possible to cure your child's cancer. However, incurable does not mean untreatable. Children with [advanced cancer](#) [3] (also called end-stage or terminal cancer) sometimes live for many months, or even years, with cancer. During this time, treatment is focused on controlling the cancer, when possible, and managing symptoms so that 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.

It is important to have open and honest conversations with your child's doctor and health care team to express your family's feelings, preferences, and concerns. The health care team is there to help, and 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**

A couple of special types of medical care are available to help with symptoms for children with advanced cancer.

**Palliative care.** This is treatment given at any stage of the disease to relieve symptoms and side effects caused by cancer or its treatment, allowing a child with cancer to live as comfortably as possible. In addition, palliative care addresses the psychological, social, and spiritual needs of the child and family. Palliative care is not an alternative to treatment to eliminate the disease; 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 is a form of palliative care provided to patients who are expected to live six months or less and who are no longer receiving treatment for the cancer. The goal of hospice care is to help patients and their families cope with the physical and emotional effects of death and dying. Because many children with advanced cancer continue to receive cancer treatments throughout the course of their illness, they may not be eligible for hospice care. Different states have different policies regarding hospice care for children, and some states do allow for cancer treatment and hospice care to be given at the same time. However, regardless of whether children are eligible for hospice while receiving cancer treatments, they can continue to receive palliative care services. 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 as well.

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, returning to the hospital periodically to receive necessary treatments. 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. As the end of life approaches, some families wish to be in the hospital, whereas others prefer to be at home. Talk with your child's health care team about the setting that feels best to you, your child, and your family.

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

Talking about death may be the most difficult step in caring for a child with advanced cancer. How and when you talk with your child about the subject is a personal decision, influenced by many factors, including the expected course of your child's cancer and your opinion about what information is appropriate to communicate to 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. Nobody knows your child better than you; you are the best judge of what to tell your child and when to say it.

Some parents believe they can protect their child by withholding the truth. However, most children with advanced cancer already know or suspect that they are dying, based on their observations of the adults around them and the changes they experience inside their bodies. It is important to be honest and open; your child will feel less anxious and alone if he or she knows what to expect. And talking about your child's death enables you and your child to have closure by sharing memories, expressing love, and saying good-bye.

Allow your child to discuss his or her fears and questions, even though it may be upsetting. 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;

however, 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**

Although talking about death and dying is always difficult, some families and individuals may find it more challenging than others, based on their family dynamics and communication styles. Ask social workers, nurses, child life psychologists, or other specialists for advice about how to talk about death with your child. In addition, the following tips may be helpful:

- 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/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.
- 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.
- 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.
- Look for signals that your child is ready to talk, such as asking questions or bringing up the subject of death.
- Look for signals that your child is done talking for the moment, such as changing the subject, looking away, fidgeting, or playing with toys. It is important to respect your child's need to drop the conversation.

The following are additional recommendations to keep in mind when talking with your child about death:

- 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."
- Have many conversations with your child, and let him or her know that you or others are always available to talk. Encourage but don't force your child to express emotions—positive and negative.
- 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. Children need to know that they made a difference in the lives of others.
- 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, because many dying children feel guilty leaving their parents, worrying 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, there are many steps you can take to help meet your child's psychosocial and physical needs. As your child's cancer progresses, the needs will change. Paying close attention to your child's behavior will help you 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 to set limits on your child's behavior and practice 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 and effectively treated.

As your child's cancer progresses and death approaches, your child 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 having a special adventure. Learn about [organizations that help children fulfill their wishes before the end of life](#) [5].
- 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.
- Stick to comfortable routines. For example, try to keep the same caregivers, if possible.
- 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, avoiding unnecessarily graphic or frightening descriptions. 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, and 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](#) [6] with other parents of children with advanced cancer. The hospital staff can help you locate a counselor or support group.
- Take advantage of offers for help from family and friends to ease your physical and emotional exhaustion. And use respite care services (patient care provided to give usual caregivers temporary relief).
- Ask the medical staff to explain symptoms that occur close to death, such as skin and respiratory changes. Knowing what to expect will help you feel more prepared and enable you to be with your child when death occurs.
- Make sure [advance directives](#) [7] and other such documents are in place before the need arises. In addition, consider making funeral arrangements and other plans?such as a decision regarding 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](#) [8].

## More Information

[How a Child Understands Cancer](#) [9]

[Grieving the Loss of a Child](#) [10]

[End-of-Life Care](#) [11]

## Additional Resources

[National Cancer Institute: When the Cancer Cannot Be Cured](#) [12]

[Hospice Net: Talking to Children About Death](#) [13] [14]

[Hospice Net: Children's Understanding of Death](#) [14]

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

### Links:

[1] <http://www.cancer.net/navigating-cancer-care/advanced-cancer/caring-terminally-ill-child-guide-parents>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/25113>

[4] <http://www.cancer.net/node/25282>

[5] <http://www.cancer.net/node/24742>

[6] <http://www.cancer.net/node/25383>

[7] <http://www.cancer.net/node/25278>

[8] <http://www.cancer.net/node/25031>

[9] <http://www.cancer.net/node/25300>

[10] <http://www.cancer.net/node/25288>

[11] <http://www.cancer.net/node/25110>

- [12] <http://www.cancer.gov/cancertopics/coping/youngpeople/page1>
- [13] <http://www.hospicenet.org/html/talking.html>
- [14] <http://www.hospicenet.org/html/understand.html>
- [15] <http://www.chpcc.org/>