

Improving Your Child's Quality of Life

Through Pediatric Palliative Care



*Treating Your Child,
Your Family, and the Disease*



Is pediatric palliative care right for your child?

Palliative care may be right for your child if they are having symptoms or side effects that interfere with their quality of life, such as:

- Pain or discomfort
- Shortness of breath
- Fatigue
- Anxiety or depression
- Lack of appetite, nausea, or constipation

Specialized palliative care services may also be needed if your child is suffering from severe symptoms or side effects of treatment or is experiencing eating problems, frequent emergency room visits, or repeated hospital admissions with the same symptoms. Because pediatric palliative care takes a whole-family approach, these services may also be helpful to you as parents and to other children/siblings in the family.

Who provides palliative care?

Your child's oncology team members (cancer doctors, nurses, and psychosocial clinicians) provide palliative care to help reduce symptoms as part of cancer treatment. They or other doctors (such as family practitioners, internists, or pediatricians) may also get help from a specialized palliative care team to work together and provide expert symptom management, extra time for communication, and dedicated help in navigating the health care system. The palliative care team may include specially trained doctors, nurses, chaplains/spiritual counselors, and social workers. Pharmacists, nutritionists, massage therapists, music therapists, child-life specialists, and others may also be part of the team. Many children's hospitals and cancer centers have these specialized teams available for consultation as part of the comprehensive cancer care services they provide.



Where is palliative care provided?

Palliative care is provided in a variety of settings where patients and survivors frequently receive their cancer-related care, including hospitals and community cancer centers. Palliative care may also be provided in the home or in long-term care facilities.



How can you get palliative care?

Ask for it! Tell your child's doctor, nurse, or other caregivers that you're interested in having palliative care as an extra layer of support alongside your child's cancer treatment to help address symptoms and other quality-of-life concerns for your child and your entire family. Most insurance plans, including Medicare and Medicaid, cover palliative care services. If costs are a concern, a social worker or other member of the palliative care team can help you. Visit getpalliativecare.org to search for a health care provider or facility near you that provides pediatric palliative care.

Where can you find more information?

If you have questions about palliative care or if it's right for you or your child, visit cancer.org or call the American Cancer Society at 1-800-227-2345. We're there when you need us – 24 hours a day, 7 days a week. For more information, you can also visit:

- getpalliativecare.org
- ninr.nih.gov/newsandinformation/conversationsmatter/conversationsmatter-videos
- courageousparentsnetwork.org

Will palliative care be available when my child or family needs it?

Palliative care is a growing medical specialty, but these services are not always available to those who need them. The American Cancer Society's advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), is working to improve access to palliative care for all adults and children with cancer and other serious illnesses. ACS CAN supports proposals to fund research and training that will help boost delivery of quality palliative care services in all care settings, while also increasing the number of specialized palliative care-trained doctors, nurses, and other health professionals. Visit acscan.org/qualityoflife for more information.



What is pediatric palliative care?

When your child is diagnosed with cancer, everyone in the family is affected. As a parent of a child with cancer, you want your child to get the best care possible – not only the most effective treatment to cure the disease, but also care that provides an extra layer of support to your child and family to reduce the psychological, emotional, and physical stresses related to cancer.

Pediatric palliative care, also called supportive care, recognizes that you are the expert about your child. It can help provide a better quality of life for your child and family by focusing on relieving the pain, symptoms, and stress associated with cancer and its treatment. It can help you, your child, and your family.

Palliative care is appropriate at any age and any stage. It can be provided from the point of diagnosis and can continue right alongside cancer treatment.

Palliative care providers understand that parents deserve to be active decision makers in their child's care. Palliative care services use a team-based approach, working with your child's other doctors and nurses to provide specialized expertise that:

- Focuses on your child's and family's quality-of-life priorities and concerns
- Assists with communication and coordination across care settings (including schools)
- Helps give your child and family a voice in determining the medical care that feels right for all of you

Palliative care specialists help parents talk to their affected child and other children about the cancer. They can provide resources to other members of the family's community – such as teachers and friends – so that they are informed of the family's needs and situation.

Written April 2016

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No. 964305 Rev. 4/16
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The American Cancer Society's nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action NetworkSM (ACS CAN), is working to make certain that palliative care is available to all people with cancer and their families. For more information, visit acscan.org.