



PALLIATIVE CARE
Conversations Matter®

Easing symptoms and enhancing lives



Palliative Care for Children

Support for the Whole Family When Your
Child Is Living with a Serious Illness



National Institute
of Nursing Research



Palliative care provides comfort and support to your child and family.

When a child is seriously ill, each person in the family is affected differently. That is why it is important that you, your child, and your family get the support and care you need during this difficult time. A special type of care called palliative (*pal-lee-uh-tiv*) care can help. Palliative care is a key part of care for children living with a serious illness. It is also an important source of support for their families. The information in this brochure will help you understand how your child and family can benefit from this type of care.

What is palliative care?

Palliative care can ease the symptoms, discomfort, and stress of serious illness for your child and family. Palliative care can help with your child's illness and give support to your family. It can:

- Ease your child's pain and other symptoms of illness.
- Provide emotional and social support that respects your family's cultural values.
- Help your child's health care providers work together and communicate with one another to support your goals.
- Start open discussions with you, your child, and your health care team about options for care.

Palliative care provides comfort for your child. Palliative care can help children and teenagers living with many serious illnesses, including genetic disorders, cancer, neurologic disorders, heart and lung conditions, and others. Palliative care is important for children at any age or stage of serious illness. It can begin as soon as you learn about your child's illness. Palliative care can help prevent symptoms and give relief from much more than physical pain. It can also enhance your child's quality of life.

Palliative care gives you and your family an added layer of support. Serious illness in a child affects everyone in the family, including parents and siblings of all ages. Palliative care gives extra support for your whole family. It can ease the stress on all of your children, your spouse, and you during a hard time.

Palliative care surrounds your family with a team of experts who work together to support all of you. It is a partnership between your child, your family, and the health care team. This team listens to your preferences and helps you think through the care options for your family. They will work with you and your child to make a care plan for your family. They can also help when your child moves from one care setting (e.g. the hospital) to another (e.g. outpatient care or care at home).

Does accepting palliative care mean our family is giving up on other treatments?

No. The purpose of palliative care is to ease your child's pain and other symptoms and provide emotional and other support to your entire family. Palliative care can help children, from newborns to young adults, and their families—at any stage of a serious illness. Palliative care works alongside other treatments your child may be receiving. In fact, your child can start getting palliative care as soon as you learn about your child's illness.

Palliative care is different from hospice care.

Your child does not need to be in hospice to get palliative care. Your child can get palliative care wherever they receive care: in the hospital, during clinic visits, or at home.

Hospice care focuses on a person's final months of life, but palliative care is available to your child at **any time** during a serious illness. Some children receive palliative care for many years.

Some hospice programs require that patients are no longer getting treatments to cure their illness, but palliative care is different—it can be given at the same time as other treatments for your child's illness.

Palliative care helps your child live a more comfortable life.

Palliative care can provide direct support for your child by providing relief from distressing symptoms, such as:

- Pain
- Shortness of breath
- Fatigue
- Depression
- Anxiety
- Nausea
- Loss of appetite
- Problems with sleep

Palliative care can help your child deal with side effects from medicines and treatments. Perhaps most important, palliative care can help enhance your child's quality of life. For example, helping to cope with concerns about school and friends might be very valuable to your child.

Palliative care may also include direct support for families such as assistance with:

- Including siblings in conversations.
- Providing respite care for parents to be able to spend time with their other children.
- Locating community resources for services such as counseling and support groups.

Palliative care is effective. Scientists have studied how palliative care can help children living with serious illnesses. Studies show that patients who get palliative care say that it helps with:

- Pain and other distressing symptoms, such as nausea or shortness of breath.
- Communication between health care providers and family members.
- Emotional support.

Other studies show that palliative care:

- Helps patients get the kinds of care they want.
- Meets the emotional, developmental, and spiritual needs of patients.

Palliative care focuses on the needs of your child and family.



How do you know if your child or family needs palliative care?

Children living with a serious illness often experience physical and emotional distress related to their disease. Emotional distress is also common among their parents, siblings, and other family members. If your child has a genetic disorder, cancer, neurologic disorder, heart or lung condition, or another serious illness, palliative care may help reduce pain and enhance quality of life.

Ask your child's health care provider about palliative care if your child or any member of your family (including you):


- Suffers from pain or other symptoms due to serious illness.
- Experiences physical pain or emotional distress that is NOT under control.
- Needs help understanding your child's health condition.
- Needs support coordinating your child's care.

Palliative care can start as soon as your child needs it.

It's never too early to start palliative care. In fact, palliative care can take place at the same time as other treatments for your child's illness. It does not depend upon the course or stage of your child's illness.

If you feel your child, your family, or you could benefit from palliative care, ask your child's health care provider about getting a referral for palliative care services. There is no reason to wait. The sooner you and your child seek palliative care services, the sooner a palliative care team can help your family manage the pain and other symptoms, and emotions that may come with a serious illness.





The palliative care team works with you, your child, and your care team.

Together with your child's health care providers, palliative care professionals will work with you and your child to make a care plan that is right for your child, your family, and you. The team will help you and your child include pain and other symptom management into every part of your child's care.

Palliative care experts spend as much time with you and your family as it takes to help you fully understand your child's condition, care options, and other needs. They also make sure your child experiences a smooth transition between the hospital and other services, such as getting care at home.

Your team will listen to your preferences and work with you and your child to plan care for all of your child's symptoms throughout the illness. This will include care for your child's current needs and flexibility for future changes.

Your child's palliative care team is unique.

Every palliative care team is different. Your child's palliative care team may include:

- Doctors
- Nurses
- Social workers
- Pharmacists
- Chaplains
- Counselors
- Child life specialists
- Nutritionists
- Art and music therapists

How can our family get palliative care?

The palliative care process can begin when your child's health care provider refers you to palliative care services. Or, you or your child can ask your provider for a referral if you feel that palliative care would be helpful for your child, your family, or yourself.

If we start palliative care, can my child still see the same primary health care provider?

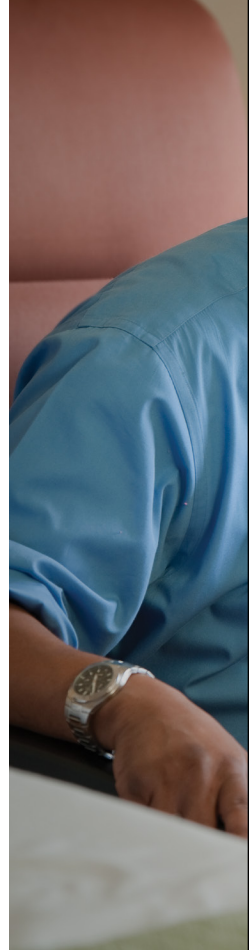
Yes. Your child does not have to change to a new primary health care provider when starting palliative care. The palliative care team and your child's health care provider work together to help you and your child decide the best care plan for your child.

What if my child's health care provider is unsure about referring us?

Some parents are afraid they might offend their child's current health care providers by asking about palliative care, but this is unlikely. Most health care providers appreciate the extra time and information the palliative care team provides to their patients. Occasionally, a clinician may not refer a patient for palliative care services. If this happens, ask for an explanation. Let your child's health care provider know why you think palliative care could help your family.

Who pays for palliative care?

Many insurance plans cover palliative care. If you have questions or concerns about costs, you can ask your health care team to put you in touch with a social worker, care manager, or financial advisor at your hospital or clinic to look at payment options.





Palliative care can begin at any time and be provided alongside other treatments your child may be receiving.

Where can my child get palliative care?

Your palliative care team will help you to know what services are available in your community. Your child and family may receive palliative care in a hospital, during clinic visits, or at home. You and your child will likely first meet with your palliative care team in the hospital or at a clinic. After the first visit, some visits may still occur in the clinic or hospital. But many palliative care programs offer services at home and in the community. Home services can occur through telephone calls or home visits.

If palliative care starts in the hospital, your care team can help your child make a successful move to your home or other health care setting.

Home may feel most comfortable and safe to you and your child. Depending on your child's condition and treatment, the palliative care team may be able to help you find a nursing agency or community care agency to support palliative care for your child at home.

How can my child's pain be managed?

The palliative care team can bring your child comfort in many ways. Treating pain often involves medication, but there are also other methods to address a child's discomfort. Your child may feel better with changes like low lighting, comfortable room temperatures, pleasant smells, guided relaxation, and deep breathing techniques. Your child may welcome additional activities like video chats, social media, soothing music, and massage and art therapy that may help decrease pain and anxiety.

If your child has an illness that causes pain that is not relieved by drugs like acetaminophen (Tylenol®) or ibuprofen (Motrin® or Advil®), your child's palliative care team may recommend trying stronger medicines. There is no reason to wait before beginning these medications. Should your child's pain increase, the dose may be safely increased over time to provide relief.

Pain relief can be offered in a hospital, at home, or in other healthcare settings. Your palliative care team will partner with you and your child to learn what is causing discomfort and how best to handle it.



Don't wait to get your child and family the extra support they deserve.



Talk to your loved ones and health care team about palliative care.

If your child wants palliative care, or if you think palliative care could be helpful to any member of your family, ask for it now. Talk with your child's health care provider about palliative care.

To see whether a hospital in your area offers a palliative care program, visit the Palliative Care Provider Directory of Hospitals at <http://getpalliativecare.org/>.

For more information about palliative care, please visit <http://www.ninr.nih.gov/conversationsmatter>.





National Institute
of Nursing Research



National Institute of Nursing Research
National Institutes of Health
<http://www.ninr.nih.gov>

July 2015
NIH publication #15-NR-8003
NIH...Turning Discovery Into Health®