



For Providers

Talking about pediatric palliative care.

As a health care provider, you are uniquely positioned to discuss options for palliative care with your pediatric patients and their families. This conversation can help educate families about palliative care, ensure clear communication between you and the family, and build their trust and confidence in you.

Who can use this pad?

You do not need to have a specialty in palliative care to use this pad. Health care professionals from any discipline or setting can engage in palliative care discussions. You can use the pad even if your hospital does not have a built-in pediatric palliative care team.

How to use this pad

This tear-off pad includes basic information about pediatric palliative care and how it can work with ongoing treatment to improve quality of life for the patient and family. The double-sided, tear-off pages inside ("For Families") can guide your discussion with your patient and the parent or caregiver.

1. **Start the discussion by providing background on palliative care.** Patients and their families are often unfamiliar with the term and what services are included.
2. **Clarify that palliative care isn't just for terminal patients.** Emphasize that palliative care can be received along with treatment, from diagnosis and during the entire course of the illness.
3. **Explain which palliative care services are available in your care setting.**
4. **Provide information on palliative care services available in your community.**
5. **Convey that this is the first of many conversations.** Suggest that the patient and/or family use the space provided on the page to write notes or questions for your next conversation.

Important tips

1. **Initiate a conversation** about palliative care with your pediatric patients and their families as soon as possible.
2. **Continue discussions** about palliative care throughout the course of your patients' illness.
3. **Developing a care plan.** The discharge planner, social worker, or care manager in your hospital or practice may be able to help you offer recommendations and arrange for any unique needs.
4. **Finding palliative care resources and providers.** If your hospital does not have a built-in pediatric palliative care team, you can find palliative care providers in your state at www.getpalliativecare.org.
5. **Paying for palliative care services.** Most insurance plans and Medicaid cover all or part of the palliative care treatment. Work with the hospital's social worker or financial consultant to help with payment options and recommendations.

See the other side of this page for FAQs and suggested responses.





For Providers:
Frequently asked
questions and
suggested responses.

1. What is palliative care and when is it provided?

- Palliative care is an important part of treatment for your child and can prevent or manage the symptoms associated with your child's illness as well as the side-effects of many primary medical treatments. It can provide relief from much more than physical discomfort, and enhance quality of life.
- It is appropriate across a range of serious illnesses or conditions and it may integrate pain and symptom management with psychosocial support such as spiritual support, counseling, and social services.
- Palliative care is available at any time during an illness, and its availability does not depend upon whether or not your child's condition can be cured.

2. Does the patient have to be in hospice care to receive palliative care?

- Your child does not need to be in hospice care to receive palliative care. Your child can receive palliative care in a hospital-based, outpatient, or home setting.

3. How can palliative care help my child and our family?

- The purpose of palliative care is to address distressing symptoms that the patient may experience such as pain, breathing difficulties, nausea, or others.
- Palliative care extends beyond patient care and includes advanced planning and coordinated care as well as support for family members, including your child's siblings.
- I can help you work with your child's other care providers to integrate palliative care services into the primary treatment plan. I can also help coordinate the delivery of your child's care.

4. Who provides palliative care?

- Palliative care is delivered by a team of professionals based on your child's needs. The palliative care team combines control of symptoms, including pain, and other support into every part of treatment. Team members will spend as much time as needed with your child and you to fully understand your child's needs. Even if your hospital does not have a formal pediatric palliative care team in place, there may be people in the hospital or groups in your area that may be able to help you and your family with palliative care services.



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For additional information and resources to help you fill out the pad:

Please visit www.ninr.nih.gov/conversationsmatter

For Families



PALLIATIVE CARE
Conversations Matter®

Easing symptoms and enhancing lives

Improving comfort and quality of life.

Palliative (pal-lee-uh-tiv) care is a key part of care for children living with a serious illness. It 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 is important for children at any age or stage of illness. It gives extra support for your whole family.

Help for your child, you, and your family during a hard time. Palliative care can help with all parts of your child's illness. It can:

- Give relief from pain and other symptoms of illness
- Provide emotional, social, and spiritual support
- Make sure all of your child's health care providers work together
- Help start open discussions on care choices for your child, such as help planning for the future

Paying for Palliative Care. Medicaid pays for palliative care. Most insurance plans will also help you pay for palliative care. Ask your child's insurance provider what they will cover for your child. If your child is not insured, see if your child can be covered by Medicaid. Visit www.medicaid.gov. Or, ask your health care team to put you in touch with a social worker, care manager, or financial consultant at your hospital to look at payment options.

Support as soon as possible. Palliative care is comprehensive treatment of the discomfort, symptoms and stress of serious illness. It works with your child's main treatment and can be given along with all other medical care. It may start as soon as your child's care begins. It can last during the whole illness. Based on your child's needs, we suggest the palliative care options below for:

[Patient name]

☐ **Pain and symptom management:** _____

☐ **Emotional, coping, or social support for your child or other family members:** _____

☐ **Spiritual or religious support:** _____

☐ **Other:** _____

Palliative care help in your community:

There are people in this hospital and groups in your area that may be able to help you and your family.

These include: _____

Your palliative care team.

Palliative care is a partnership between your child, your family, and the health care team. This team helps you know what care choices your child and family have. They will work with you and your child to make a care plan just for you. They will help your child move smoothly from the hospital to outpatient care, or getting care at home.

A palliative care team may have:

- Doctors
- Nurses
- Social workers
- Pharmacists
- Religious or spiritual advisors
- Counselors
- Therapists
- Nutritionists and others

Suggested members of your palliative care team:

Name/Title: _____

Contact Information: _____

Name/Title: _____

Contact Information: _____

Name/Title: _____

Contact Information: _____

Name/Title: _____

Contact Information: _____

Name/Title: _____

Contact Information: _____

Name/Title: _____

Contact Information: _____

Ongoing care when you need it. This is the first of many conversations you will have about palliative care. Your child’s needs may change. So, it is important to keep talking about options for care throughout your child’s entire illness.

Let’s plan to talk about your child’s care again on: _____
[insert date]

And check on your child’s and family’s needs every: _____ **weeks.**

Other Suggestions: _____

Your notes on palliative care

Use this space to take notes and to track your child’s progress. You may also want to write down questions to ask the palliative care team.

Notes/Questions: _____



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