



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 provider and family, and build their trust and confidence in you.

Before getting started, here are some tips:

- Initiate a conversation about palliative care with your pediatric patients and their families as soon as possible.
- Continue discussions about palliative care throughout the course of your patient's illness.
- Listen to the patients and their families to understand their unique needs.
- Ensure your patients and their families understand that:
 - Receiving palliative care does not mean that active medical treatments, curative care, or life-prolonging care will stop.
- Provide clear, easy-to-understand information and materials about palliative care.

Instructions on how to use the front of this pad.

You can use the front of this tear pad as an interactive discussion tool to guide your conversations about pediatric palliative care. The following steps correspond to each section on the front of the pad and can help you start and manage the conversation.

- 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. Ensure your patients and their families understand that palliative care should be initiated as soon as possible and continued throughout the course of the illness.** Explain which palliative care services are available in your care setting, check the boxes of services appropriate for the patient, and use the space provided below each box to make specific recommendations on appropriate care.
- 3. Provide information about the different members of a palliative care team and use the space provided to recommend a team for the patient and his or her family.** If additional resources are available in your care setting or community, fill in the *Palliative care resources* section.

Note: You can update this section with a sticker listing available resources.

- 4. It is important to convey to patients and their families that this is the first of many conversations.** Fill in the space provided with a date and recurring time frame for when the patient's care will be discussed.

Reiterate that palliative care provides support for patients and family members during this difficult time. Suggest that the patient and/or family use the space provided for notes or questions for your next conversation.



PALLIATIVE CARE

Conversations Matter

Easing symptoms and enhancing lives

Information & Resources for Families

Improving comfort and quality of life.

Palliative (pal-lee-uh-tiv) care is a key part of treatment for children living with serious illnesses or life-limiting conditions. It can help prevent symptoms, give relief from much more than physical pain, and enhance quality of life for your child. Palliative care is important no matter your child's age or stage of illness. It gives an added layer of support for your whole family.

Support for your child, you, and your family during a difficult time.

Palliative care gives support for all aspects of your child's illness:

- Relief from pain and other symptoms of serious illness
- Emotional, psychosocial, and spiritual support services
- Coordination of care with all of your child's health care providers
- Open discussions about treatment choices for your child, such as help in making important care decisions and advanced care planning

Support as soon as possible. Palliative care works along with your child's main treatment. It can be provided along with all other medical treatments. It may start as soon as your child's treatment begins and can continue during the whole illness. Based on your child's needs, we recommend 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 resources in your community:

There are resources in this hospital and in your community that may offer support to you and your family.

Resources include:

Your palliative care team. Palliative care is a partnership between the child, the family, and a team of specialists. These team members help you fully understand your child's and family's care choices. They will work with you and your child to make a care plan just for you. They will help your child make a smooth transition from the hospital to outpatient care, or care received at home.

A palliative care team may include:

- Doctors
- Nurses
- Social workers
- Pharmacists
- Chaplains
- Counselors
- Nutritionists and others

Recommended members of your palliative care team:

Name: _____

Phone: _____ Title: _____

Name: _____

Phone: _____ Title: _____

Name: _____

Phone: _____ Title: _____

Ongoing care when you need it. This is the first of many conversations you will have about palliative care. It is important to keep talking about options for care throughout the course of your child's illness to meet his or her changing needs.

Let's plan to talk about your child's care again on:

_____ [insert date]

And reassess your child's and family's needs every: _____ weeks.

Additional Recommendations:

Your notes about 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:

**For more information about palliative care, please visit
www.ninr.nih.gov/conversationsmatter.**



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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.

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



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U.S. Department of Health
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**National Institute of Nursing Research
National Institutes of Health
31 Center Drive, Room 5B10
Bethesda, Maryland 20892-2178
www.ninr.nih.gov**