



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.

Who can use this pad?

This tear-off pad was designed to help health care professionals from any discipline working in any setting engage in interactive palliative care discussions with pediatric patients and their families. You do not need to have a specialty in palliative care to use this tool. Additionally, you can use the pad even if your hospital does not have a built-in pediatric palliative care team. See the back side of this page for information and resources to help you use this tool.

Instructions on how to use this pad.

This pad includes basic information about pediatric palliative care and explains how it can work with ongoing treatment to help improve quality of life for the patient and family. The front and back covers of this tear-off pad have information for you—the health care provider. The 50, double-sided patient pages in between are meant to guide the discussion with your patient and his/her parent or caregiver. The pages allow you to customize your recommendations based on the patient's and family's individual knowledge, past experiences, needs, and interests. The following steps correspond to each section on the patient pages of the pad.

- 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. 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 additional palliative care services in your community.** This might include home-based care teams, tertiary care facilities, community health centers, or a local social worker or faith leader experienced in palliative care.
Note: Your hospital or practice setting may be able to provide you with information about available resources. Consider working with your hospital to create a sticker listing resources in your community to affix over the *Palliative care help in your community* section.
- 4. 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.** Include the names and contact information of the recommended team (e.g., social worker, chaplain, dietitian, home health aide, etc.).
- 5. 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.

Where can I find additional information and resources to help me fill out the pad?

- **Developing a care plan.** The discharge planner, social worker, or care manager in your hospital or practice may be able to help you think through various options for your patient's care plan, offer recommendations, and make arrangements for your patient and their caregiver's unique needs.
- **Finding palliative care resources and providers.** Even if your hospital does not have a built-in pediatric palliative care team, you may still be able to help your patients and their families access these important services. You can find palliative care providers in your state at <http://www.getpalliativecare.org/>.
- **Paying for palliative care services.** Remember, most insurance plans cover all or part of the palliative care treatment, just as with other hospital and medical services. This is also true of Medicaid. However, each state might have different policies. If costs are a concern for the family, work with the hospital's social worker or financial consultant to help with payment options and recommendations.

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 patients' illness.
- Listen to your 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.
 - Palliative care can start at diagnosis and continue during the entire course of the illness.
- Provide clear, easy-to-understand information and materials about palliative care.

For more information on palliative care and additional instructions on using this pad, please visit www.ninr.nih.gov/conversationsmatter.



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For Families

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
- Chaplains
- Counselors
- Nutritionists and others

Suggested 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. 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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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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