Finding Family Support

Pediatric Palliative Care Tips

A child’s serious illness affects the entire family. Although the palliative care team is your best resource, here are additional supports that may improve your family’s quality of life.

Support Groups

Support groups can be a source of comfort and connection during difficult experiences. They come in many forms and are now available online and in person.

A support group is typically led by a peer (e.g., survivor) or mental health specialist. Some groups are specifically for patients or parents while others welcome the whole family, including siblings and grandparents. The focus of conversation can also vary. Some groups discuss a specific illness or symptom and others provide more general family support.

Sibling Support

When a child is ill, siblings may feel displaced or resentful, and potentially guilty about those feelings. Young siblings may be afraid or confused. It is important that support extend to brothers and sisters who need to express emotions or take a break. Talk to your children about their needs and ways they might like to receive support, such as:

- Music and arts
- Sibling camp
- Counseling
- Tutoring
- Peer play
- Support groups

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.
Respite Care
Taking a break from caregiving is important. Provided in or out of the home, respite care ranges from a few hours to overnight. Think about what you need most. Maybe that is time to run errands or relax. How often do you need that time? These and other factors, like your child’s mobility, will tell you what type of program is best for you.

School Resources
By law, students must be able to continue education in school, in a clinical setting, or at home. To develop a plan, meet with the school counselor and nurse to discuss questions and concerns. Talk to teachers, who can usually customize work for your child. And, if appropriate, ask about helping classmates understand your child’s illness.

Local Resources
Start by asking your child’s health care provider and palliative care team for ideas. Check your hospital or clinic bulletin board and website for posts. Search online for city and county resource guides. A local organization focused on your child’s illness may also have suggestions.

Online Resources
Look for websites, including social media like Facebook, that help you connect with friends, relatives, and other families with similar experiences. There are even sites that allow you to create private web pages, making it easier to update loved ones.

For more resources, visit: http://nintr.nih.gov/conversationsmatter

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