

Appendix E: Pediatric Palliative Care Tips: Finding Support

Children with serious illnesses often experience physical and emotional distress related to their condition. Emotional distress is also common among their family members. Additional support can help you improve your family’s quality of life. Although the palliative care team is your best resource, this sheet can help you think about other supports that might benefit your family.

Support Groups

Support groups can be a source of comfort and connection during difficult experiences. They are not the same as formal mental health treatments like group therapy. Support groups come in many forms and there is no rule for picking the right one. Start by using these lists to narrow down what might be best for you.

Leader	Participants	Format	Focus
<ul style="list-style-type: none"> •Peer (patient, survivor, or family member) •Professional (mental health or other specialist) 	<ul style="list-style-type: none"> •Patients only •Siblings only •Parents and other adult relatives •Open to entire families 	<ul style="list-style-type: none"> •In-person meetings •Online meetings •Discussion boards and blogs 	<ul style="list-style-type: none"> •Targeted (e.g., coping with pain) •Condition-specific •Caregivers •General family support

Respite Care

Respite care provides short-term rest from the daily challenges of caring for someone with special health needs. It provides time for you to take a break – a key part of being a good caregiver. Provided in or out of your home, care can range from a few hours to overnight. Use these questions to start thinking about the best option for you.

- What do I need most out of my respite time? (Work or errand time, relaxation, etc.)
- Do I want to spend this time inside or outside of my home?
- Will my child benefit from time with other kids and new surroundings in an out-of-home program?
- Will transportation to an out-of-home program be challenging?
- How often do I need respite care?

Sibling Support

A child’s serious illness affects the whole family, including siblings who may experience a range of reactions. It is common for siblings to feel displaced or resentful, and potentially guilty about those feelings. Young siblings may be afraid or misunderstand what is happening. It is important that support extend to brothers and sisters who need to express their emotions or just take a break. Start by talking to your children about their concerns and how they want to be supported.



School Resources

By law, all students must receive accommodation to continue education in school, in a clinical setting, or at home. Work with your child's school to develop a plan:

- Meet with the school counselor and school nurse. They can help with concerns you have, including what happens in case of emergency.
- Talk to your child's teachers, who can usually customize work based on your needs. Ask what materials you can take home to help your child keep up.
- Ask about activities that may help classmates understand your child's illness.

Local Resources

Even if you have lived in your community for years, it can be hard to know what resources are available. Here are a few ideas to help you find support in your area.

- Ask your child's health care provider and palliative care team for suggestions.
- Check your hospital or clinic bulletin board or website for relevant posts.
- Search online for a city, state, or county resource guide.
- Contact an organization focused on your child's illness.

Online Resources

Look for websites that help you connect with friends, relatives, and other families. There are even sites that allow you to create private online communities.

Social media is another way to find resources. Use key words, such as your child's illness, to search for people and groups on sites like Facebook. Twitter chats, which often have expert guests, may also be helpful.

Hashtags to Watch

#palliativecare
#palliative
#pedpc

For more information, including a list of specific resources, visit the *Palliative Care: Conversations Matter*[®] campaign at <http://ninr.nih.gov/conversationsmatter>.

NINR will select photos for this piece of the Family Information Kit from this collection of images.

