

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

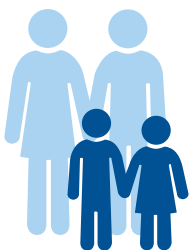
Support groups can be a source of comfort and connection during difficult experiences. They come in many forms and are now available online and in person.



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

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://ninr.nih.gov/conversationsmatter>



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