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Appendix D





Pediatric Palliative Care at a Glance

A child's serious illness affects the entire family. Pediatric palliative (*pal-lee-uh-tiv*) care can support everyone. Whether you are having difficulty managing your child's condition and care or simply want extra support, palliative care can help.

What is pediatric palliative care?

Pediatric palliative care is supportive care for children with serious illnesses and their families. It offers an added layer of support based on your unique needs. Because you are the expert on your child and family, palliative care provides services that you consider important. It can help:

- Ease your child's pain and other symptoms
- Provide emotional support and reduce stress
- Address family concerns
- Communicate with health providers

Many children need more than relief from symptoms. Palliative care can also help your child:

- Understand a diagnosis
- Communicate effectively with doctors
- Cope with concerns about school and friends

When can care start?

Palliative care can help children at any age or stage of a serious illness, from diagnosis forward. It is available at the same time as any other treatments doctors may prescribe and can begin as soon as your child needs it. Care for your child and family can begin when your child's health care provider refers you to palliative care services. The provider may suggest a referral, or you can request one.

ENHANCING QUALITY OF LIFE FOR YOUR CHILD AND FAMILY

• Coordinate care and appointments

Find ways to relax and play

• Explain complicated terms and care options

Receive services, like art or music therapy

 Locate community resources to help your family

Care Connection Comfort Communication Comfort Coordination



How does it work?

Palliative care surrounds your family with a team of specialists who will listen to your needs and work together to meet them.

Art and music therapists

Every palliative care team is different. Your team may include:

- Doctors
- Nurses
- Child life specialists
- Respite providers
- Where is care provided?

Palliative care can be provided in a hospital, during clinic visits, or at home. If palliative care starts in the hospital, your team can help your child make a successful move to your home or other health care setting. Depending on your child's condition and treatment, the care team may be able to find a nursing or community care agency to support care at home.

Who pays for care?

Many insurance plans cover palliative care. Ask your health care team to put you in touch with a social worker, case manager, or financial advisor at your hospital or clinic to learn about payment options.

What next?

- Talk to your loved ones, including your child, about how palliative care can support your family. Remember, even young children can express their needs and preferences.
- Talk to your child's health care provider. Prepare by writing down your family's questions about palliative care. It may also help to take notes during the conversation.
- Visit the Palliative Care Provider Directory of Hospitals to see whether a hospital in your area offers a palliative care program: <u>http://getpalliativecare.org/</u>.
- Find additional information and resources: <u>http://www.ninr.nih.gov/conversationsmatter</u>.





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- Home health aides
- Social workers
- Nutritionists
- Pharmacists

YOU DON'T HAVE TO BE IN A HOSPITAL TO GET PALLIATIVE CARE.

Case managers

Chaplains

Counselors